

# The Future of PIP: a social model-based approach



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# Contents

Executive Summary

1. Introduction

2. The Role of DLA and PIP

3. The Abolition of DLA and the Introduction of PIP

4. The Future of PIP: an alternative vision

Acknowledgements

## Executive Summary

In December 2010, the Government announced plans to replace Disability Living Allowance with a new benefit: the Personal Independence Payment (PIP). The policy objective of PIP is to act as a “more active and enabling benefit that supports disabled people to overcome the barriers they face to leading full and independent lives.”<sup>1</sup> This aim is most welcome, but there is great concern over particular aspects of the Government’s plans for reform.

In particular, we strongly oppose the plans to cut the DLA/PIP budget by 20%. We remain very concerned that this decision is based purely upon on budgetary targets, rather than on robust evidence as to how the benefit is used and by whom. We believe this cut will have a direct impact on the assessment process, and could well see those who face particularly high barriers and disability costs, which are not captured by a medical assessment process, lose out on a most vital lifeline of support and be pushed further into poverty as a result.

There is also widespread agreement across the disability sector that the assessment with which the Government plans to assess eligibility for PIP is not fit for purpose. The assessment – the principles underlying it; the activities it focuses on, and the draft descriptors – goes against the Government’s stated commitment to adopting a social model for DLA reform.<sup>2</sup> The primary arguments made in this report are:

- That the assessment and the principles underlying it are highly medical, and there is not enough consideration of the social model of disability.
- That the assessment will be of limited use in achieving the objectives of reform.
- That the aims of achieving an assessment that is both totally ‘objective’ and accurate, and that achieves its original objectives for reform, contradict one another; and
- That the draft assessment criteria against which prospective recipients are to be assessed is restricted to the point of being counter to the original purpose of both PIP and its predecessor, DLA. That is, as a benefit designed to contribute towards meeting the additional costs of disability.

Focusing only on the barriers that arise directly as a result of the limitations caused by their impairment or health condition will only ever show some of the picture of the barriers disabled people face to participating in society and leading the lives they value. It is well known – and demonstrated by research – that disabled people face a plethora of barriers to participation and independence – many of which come not as a consequence of an individual’s limitations as caused by their impairment or condition, but as a direct result of social, practical and environmental factors. That the assessment pays no consideration to external barriers undermines the commitment made by the Government to the social model of disability.<sup>3</sup>

Highlighted here in this report are deep-rooted, fundamental flaws – not just with the draft assessment – with the whole approach to conceptualising the barriers disabled people face.

In the second half of this paper, we outline a blueprint for an alternative vision as to how the assessment process for PIP might be considered. The approach set out

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<sup>1</sup> DWP *DLA Reform – impact assessment*, Oct 2011, <http://www.dwp.gov.uk/docs/dla-reform-wr2011-ia.pdf> (accessed October 2011)

<sup>2</sup> Miller, M, *Hansard*, 30 Nov 2010, col 220WH, <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101130/halltext/101130h0001.htm#10113030000270> (accessed September 2011)

<sup>3</sup> DWP *Public consultation Disability Living Allowance reform* (The Stationary Office: London, 2010)

here genuinely seeks to capture the barriers that a disabled person faces in their everyday life, and what effect these have on their capability for choice and control, participation and independence. This model has been strongly influenced and informed by our own research with the think tank Demos; our discussions with disabled people; and the input and ideas we received during two days of workshops with representatives from disability charities, disabled people's organisations, think tanks, academic institutions, information and advice charities, local authorities and transition services.

We recommend the trial of an approach that

- **Takes greater account of the social model of disability**, by accounting for the social, practical and environmental barriers – and disability costs that come with these – as well as how an individual manages or copes with their condition or impairment;
- **Is co-produced with the claimant**, and not done 'to' them. We retain serious concerns that the assessment for PIP making the same mistakes as those pointed out by Malcolm Harrington in his review of the Work Capability Assessment (WCA) – that it is “impersonal” and “mechanistic” and “lacks communication” between the parties involved. We strongly believe that the PIP assessment needs to take the form of a conversation between the prospective recipient and the assessor, and believe there are very valuable lessons to be learned from person-centred planning, transition plans, and support plans used in Personal Budgets and Direct Payments.
- **Is better designed to helping disabled people overcome the barriers they face**, by ensuring that those facing significant external barriers, which could be reduced or removed by intervention from services (housing, for example, or Motability) are passported onto the relevant services. This already occurs in other assessments, and would be hugely beneficial to both the lives of disabled people receiving PIP, but, we believe, also to Government as the removal of barriers and costs would reduce the need for PIP, and ultimately lead to lower spending on the benefit over the long term.

Our approach incorporates the following steps:

1. **An initial preparation stage**, which encourages the claimant to submit any existing relevant evidence, like a transition plan, person-centred or support plan, which could be used to begin the conversation between the assessor and the prospective recipient. At this stage – the beginning of the pathway – the prospective recipient could also seek advocacy support – from sources such as an individual or a group; peer support network; formal, professional, paid, legal or citizen advocacy; a support or key worker; friend, neighbour or family member, or anyone else.
2. **A more multidimensional assessment that places greater emphasis on the social model of disability**. This would be co-produced between both the assessor and the prospective recipient. It would consider the impact of impairment(s) or health condition in terms of condition management (*i.e.* how the individual manages their condition on a day-to-day basis); and the social, practical and environmental barriers that prevent the individual from leading an independent life. The assessment would combine both a points-based,

scoring approach<sup>4</sup> **and** a semi-structured interview format, so as to ensure that the assessor gains as good an understanding as possible of the barriers that prevent the disabled person from living the full and independent life they value. Such an assessment might ask them for:

- Details of their general circumstances (including: who they live with, and any dependents for whom they have to provide support).
- Information about the current problems and issues they are experiencing;
- The activities the individual undertakes as part of their weekly life:
  - ⇒ How they manage – their needs and coping strategies;
  - ⇒ How and if they are supported, and, if so, in what way;
  - ⇒ The barriers they face when undertaking the activity; and
  - ⇒ How they would like to be able to do the activity; what would make their life easier.
- Attempting to design descriptors that capture the whole range of activities – and the barriers and disability costs that come with them – potentially risks making the assessment complex and unwieldy. Instead, we suggest that the assessor gets the prospective recipient to provide information about the activities that they feel are important to them.
- They would then be asked a series of probing questions that may enable the assessor to understand:
  - ⇒ The way in which the person carries out the activity;
  - ⇒ How they usually manage when doing so;
  - ⇒ How – if – they are supported, in what way, and by whom; and
  - ⇒ How they would like to be able to do the activity in question.
- The process could then be repeated for several activities, each of which would fall into one of four categories: **Condition Management** (how the disabled person manages their condition or impairment); **Participation** (any barriers they face to social, economic, cultural, religious/spiritual participation); **Home and Family life** (what issues arise – as a direct or indirect result of their impairment or condition – when trying to attend to family duties); and **Independent Living** (what barriers they face to living as independently as they would like to).<sup>5</sup>
- **They would be scored according to the impact of certain barriers – both as a direct result of their impairment or condition and as a result of external factors like inaccessible transport, inadequate housing or lack of support networks. They would receive an amalgamated score across barriers, which would determine their eligibility for PIP, and whether this would be for a single higher, middle or lower rate.**

### 3. Introducing an indicative decision stage, which we believe would greatly improve the transparency of the process, as well as the inclusion of the views

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<sup>4</sup> But this would be more akin to the approach used in Self Assessment Questions (SAQs) for Personal Budgets, as opposed to that used in Work Capability Assessments (WCAs).

<sup>5</sup> These categories were decided upon over the course of an expert workshop, facilitated by Scope and attended by representatives from Disabled People's Organisations, disability charities, local authorities, academic institutions and think tanks.

of the prospective recipient, who could at this point submit extra evidence if they disagreed with the proposed decision.

4. **Final decision** by a DWP decision maker. Should the applicant wish to challenge this decision, they can appeal.
5. **The production of a Local Support Plan**, which would capture the evidence and information brought up over the course of the assessment process, and which would help highlight where in the individual's life their barriers and their needs tend to arise. This could help the claimant identify particular areas in which PIP might provide valuable support meeting disability costs, but would **not** take the form of an outcomes-based agreement binding the individual to use their PIP for specific purposes. Moreover, it would be used to flag where in their life additional support from national and local services could help with reducing or removing long-term barriers. The claimant would be passported to a local triage solution, as the plan would show what support they could do with in their community. This would be of benefit to everyone who undergoes a PIP assessment, as some may not be considered entitled to PIP, but may well be thought to benefit from help from such services.

In addition to this pathway, and the stages included within it, this report also sets out the following recommendations:

- **That an assessment based on the social model of disability needs to be carried out by appropriately selected assessors with expert knowledge of the barriers disabled people face.** If DLA reform is to be centred on the social model of disability, we do not believe it is appropriate for assessments at the centre of this reform to be conducted by medical professionals. The roll out of the personalisation agenda has resulted in a wealth of professionals who we believe would be better placed to carrying out an assessment of the type suggested here. These could be experts with experience in person-centred planning, transition plans, support plans, social care, and other areas (which would be expanded and refined with testing and trialling.)
- **That an assessment process based on the social model of disability needs a less medical system of verification.** While we would be very quick to point out the extremely low (0.5%)<sup>6</sup> levels of fraud for DLA, we understand the Government's concerns about verification. Yet, we strongly believe that it is not appropriate to revert back to the medical model in this instance, and so we suggest that the prospective recipient is made to submit – during the initial preparation stage – a supporting statement in the form of a reference from an eligible profession (the list of which could be expanded and refined during the testing and trialling process) – as similarly used with applications for official documents like passports, etc.

This paper – and the recommendations set out within it – is the result of an on-going conversation, dating back almost a year, with Government officials, and much of the wider disability sector. We welcome the interest of and engagement by Government in this project and its findings, and would welcome the opportunity to discuss these ideas further.

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<sup>6</sup> Information Directorate Fraud and Error Measurement *First Release* - Fraud and Error in the Benefit System: Preliminary 2010/11 Estimates, DWP, <http://research.dwp.gov.uk/asd/asd2/fem/nsfr-final-120711.pdf> (accessed October 2011)

The arguments and ideas presented in this paper have been influenced and informed by both new and existing research. Set out here is an alternative vision of what PIP could – and should – look like: the journey that claimants should take, a more multi-dimensional assessment with which to determine eligibility, and ideas as to how the Government might intervene on a wider scale to lower the barriers disabled people face, and adopt more long-term view on tackling disability poverty.

## Introduction

### Context

In December 2010, the Government announced plans to replace Disability Living Allowance (DLA) with a new benefit: the Personal Independence Payment (PIP). Underlying the introduction of PIP is the aim of creating “a new more active and enabling benefit that supports disabled people to overcome the barriers they face to leading full and independent lives.”<sup>7</sup> Speaking about the reforms to DLA (alongside a raft of other changes to the welfare benefits system), the Minister asserted: “the very clear objective of the government is that we are supporting disabled people to live more independent lives”.<sup>8</sup>

These aims are most welcome. Indeed, many individuals, charities (including Scope) and organisations agree that DLA is in need of reform. The current DLA application process – via a self-assessment form – is complex and convoluted. It is also heavily centred on the medical model of disability, which reduces an individual’s disability to their impairment or condition; and is also grounded in a ‘deficit approach’ – focusing on what the individual is *not* able to do because of their impairment. This can make the process of applying extremely arduous – and especially for parents of disabled children.

However, any consensus between the Government and disabled people, charities and disabled people’s organisations (DPOs) has been overshadowed by significant concerns and strong disagreement surrounding other aspects of the Government’s plan for DLA Reform. These include the ambition of reducing the budget by 20%; extending the backwards test of the Qualifying Period by a further three months, effectively doubling the length of time a new PIP claimant has to wait before they can access much-needed support; and the removal of the PIP mobility component from people living in state-funded residential care.

*Note: although this paper sets out an alternative vision for PIP, which, we believe, will enable PIP to be better targeted, we are strongly opposed to the Government’s plan to reduce the budget for PIP by 20%, which we believe will result in many disabled people losing out on a lifeline of support.*

There was also strong agreement across the disability sector about the assessment with which the Government plans to assess eligibility for PIP. Prior to publishing the initial draft assessment criteria, the Minister for Disabled People declared that the Government was “absolutely committed to a social model for [DLA reform], not a medical model”.<sup>9</sup> And yet, the initial draft criteria for the assessment as it currently stands does remain very much centred on the medical model of disability, constrained by a limited range of activities and retaining “a strong focus on care and mobility” as well as “the impact of a health condition or impairment.”<sup>10</sup> The criteria, the Government points out, is ‘less medical’ [than that under the DLA system] as it is “not based on the type of impairment individuals have but how these affect their

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<sup>7</sup> DWP *Disability Living Allowance Reform – Impact Assessment* (London: DWP, 2011)

<sup>8</sup> Miller, M, quoted in Gentlemen, A ‘Disability benefits reforms: Minister undeterred by campaigners’ anger’, February 2011, <http://www.guardian.co.uk/society/2011/feb/16/aria-miller-disability-minister-benefits-reform> (accessed September 2011)

<sup>9</sup> Miller, M, *Hansard*, 30 Nov 2010, col 220WH, <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101130/halltext/101130h0001.htm#10113030000270> (accessed September 2011)

<sup>10</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

everyday lives”.<sup>11</sup> At a glance, this assertion does not seem unreasonable at all. Yet, as demonstrated later in this paper, that the assessment criteria proposed remains centred on care and mobility and impact of impairment – all of which are intrinsic to the medical model – means it will fail to result in an accurate reflection of the social, practical and environmental barriers – and the extra disability costs that come with these – that disabled people face in their everyday lives. This is highly significant as it is precisely these costs that DLA – and its successor, PIP – is designed to contribute towards. Failing to pay greater consideration to other factors – like barriers resulting from inappropriate housing, inaccessible transport or social isolation – will result in a benefit that is poorly targeted and not properly fit for purpose. Ultimately, it will be counterproductive to the Government’s very laudable aim of supporting “disabled people to overcome the barriers they face to leading full and independent lives.”<sup>12</sup>

When the Government published the initial draft criteria for the assessment, it was met with much criticism from the disability sector. In its ‘comments’ on the criteria, the Disability Benefits Consortium (a coalition of 51 disability charities) stated: “a more holistic, multidimensional approach to assessing the additional costs and barriers to participation experienced by disabled people would be far better than the tick box methodology that has been proposed.”<sup>13</sup> Disability Alliance was also highly critical of the assessment that has been proposed: “we are very disappointed with the considerably limited set of essential activities despite the DWP emphasis that the PIP is being designed to support disabled people to be active and independent.”<sup>14</sup> In our own response, Scope emphasised our serious concerns “that failing to account for social and environmental factors that drive up disabled people’s additional costs will result in PIP being poorly targeted and many disabled people – especially those assessed as having low impact of impairment but high disability-related costs – missing out on critical financial support”. In both conversations we have had with DWP, and in our written evidence to the Work and Pensions Select Committee, which is conducting an inquiry into DLA Reform (which focuses on the design and delivery of the PIP assessment, among other things), we have urged the Government to reconsider the initial draft criteria proposed for the assessment – and instead to explore developing an alternative model that is much more multidimensional in scope.

This paper – and the recommendations set out within it – is the result of an on-going conversation, dating back almost a year, with Government officials – a conversation in which we have stressed our concerns – supported by evidence and research – about an assessment for PIP that does not account for the very real barriers and disability-related costs that prevent disabled people from having choice and control and leading the lives they value. And while the Government has thus far chosen to continue to press ahead with its reforms – announcing the introduction of PIP before the consultation on DLA had finished; training assessors and trialling the draft assessment criteria before the period for receiving comments on the draft had ended – demonstrated in this paper is that there is an alternative. That said, we welcome the interest of and engagement by Government in this project and its findings, and would welcome the opportunity to discuss these ideas further.

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<sup>11</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

<sup>12</sup> DWP *Disability Living Allowance Reform – Impact Assessment* (London: DWP, 2011)

<sup>13</sup> Disability Benefits Consortium ‘DBC draft pip regulation comments’, June 2011, <http://www.disabilityalliance.org/dbcpip.htm> (accessed September 2011)

<sup>14</sup> Disability Alliance *Personal Independence Payment – DWP initial draft assessment - Disability Alliance response: June 2011*, June 2011, <http://www.disabilitywales.org/2924.file.dld> (accessed September 2011)

The arguments and ideas presented in this paper have been influenced and informed by both new and existing research. Set out here is an alternative vision of what PIP could – and should – look like: the journey that claimants should take, a more multi-dimensional assessment with which to determine eligibility, and ideas as to how the Government might intervene on a wider scale to lower the barriers disabled people face, and adopt a more long-term view on tackling disability poverty.

## **Methodology**

This report draws on the findings of both new and existing research. In December 2010, the independent think tank Demos published new research, commissioned by Scope, on disability-related costs, which included analysis of a survey of 845 disabled people and parents of disabled children.<sup>15</sup>

Over summer, Scope also facilitated two expert workshops, which were attended by a wide range of representatives from other organisations (see acknowledgements), including disability charities, services, academic institutions, think tanks and DPOs. Limited time and resources prevented us from conducting a more extensive programme of research. Ultimately, what is put forth here is a blueprint for reform – to be taken and investigated further, tested and trialed.

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<sup>15</sup> Wood, C & Grant, E *Counting the Cost* (London: Demos, 2010)

## The Role of DLA and PIP: covering costs, lowering barriers

### Background

DLA was introduced in 1992 as a non-means tested benefit designed to contribute to meeting the extra costs of disability.<sup>16</sup> DWP research shows that DLA is a highly valued source of support and seen by those who receive it as helping them maintain control and independence, and improve their quality of life, among other very positive outcomes.<sup>17</sup> It is also seen to help enable disabled people to work, live at home and out of residential care, and keep people – who might otherwise be socially isolated – participating in social life.<sup>18</sup> DLA is used in a multitude of ways; the recipient decides how best to spend it to meet their needs. However, research shows that the benefit is frequently used to meet the additional expenses of social activities; personal care; healthcare, medical equipment and supplies; telephones and computers; food; fuel; helping a disabled person maintain their home; and to buy presents for friends and family who carry out (informal) care duties.<sup>19</sup>

*“I use my DLA to pay for my ironing and buy gifts for my family who help with cooking and cleaning and doing tasks when I am too tired or my limbs are not fully functioning – usually at the end of the day having been at work all day!” – respondent to survey, 2010*

*“I use my DLA to pay for repairs to my electric component of my wheelchair, the car and the hoist. We have to spend more on heating, because I feel the cold terribly and the pain from stiff muscles can be unbearable.” – respondent to survey, 2010*

In 2010, the polling company ComRes conducted a survey, on behalf of Scope, of disabled people and parents of disabled children, asking them about the barriers they face and the additional costs they use their DLA to cover. This helped capture a wealth of data about the barriers disabled people face and the areas in which it is much more expensive to live as a person with a health condition or impairment. These include (but are not limited to) inaccessible transport; unsuitable housing; managing a condition or impairment in ways that are frequently not covered by the NHS (e.g.) alternative therapies, massage, etc.; extra, often prohibitive costs incurred when undertaking a social activity (e.g. having to cover the travel costs incurred by a carer, or an extra seat at the cinema, etc.).

### Transport

One of the most frequent barriers disabled people and people with mental health conditions face in their everyday lives is that of inaccessible public transport – which, for many, means that they have to pay significant sums of money to take taxis or private transport to do the things they want to do.

*“A lot of times if public transport goes down late at night or is overcrowded such that it feels unsafe (worried about falling and getting injured again- 2 broken bones related to travel by public transport in past 3 years makes me nervous) end up paying for cabs or minicabs out of my own pocket. Not frequent – but expensive and key to feeling safe. The other reason that I'd take a cab is having to carry heavy groceries or other*

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<sup>16</sup> Corden, A et al, *The impact of Disability Living Allowance and Attendance Allowance: findings from exploratory qualitative research*, DWP Research Report 649 (London: DWP, 2010)

<sup>17</sup> Corden, A et al, *The impact of Disability Living Allowance and Attendance Allowance: findings from exploratory qualitative research*, DWP Research Report 649 (London: DWP, 2010)

<sup>18</sup> Corden, A et al, *The impact of Disability Living Allowance and Attendance Allowance: findings from exploratory qualitative research*, DWP Research Report 649 (London: DWP, 2010)

<sup>19</sup> Corden, A et al, *The impact of Disability Living Allowance and Attendance Allowance: findings from exploratory qualitative research*, DWP Research Report 649 (London: DWP, 2010)

*awkward purchases - don't have as much strength on right side and have had a seizure within the last year so can't drive at present.*" – respondent to survey, 2010.

A recent survey of over 2,000 disabled people, conducted by the Papworth Trust, showed that over half of disabled people who receive DLA use it to pay for specialist transport.<sup>20</sup> Analysis by the independent think tank Demos, commissioned by Scope, demonstrated that disabled people who had to rely on public transport had significantly higher costs than those who did not, often because they had to pay for private transport when public alternatives are not suitable or inaccessible.

*"I pay for taxis when taking bags on the bus/tube would be too difficult or when the route has too many changes or when I don't know how far it is from the nearest bus/tube to where I need to go."* – survey respondent, 2010

Research by other organisations reaches similar conclusions. A 2009 study by Leonard Cheshire Disability reported that 58% of disabled people found stations or terminals inaccessible; 64% found the mode of transport inaccessible.<sup>21</sup> Such evidence serves to demonstrate that despite transport service providers being required (since 2006) to make reasonable adjustments to ensure they offer an accessible service to disabled people, in reality, this has not translated into real improvements to accessibility.<sup>22</sup> As a result, many disabled people have to pay extra for private alternatives just so they can undertake everyday activities like shopping for food or seeing family and friends.

### *Housing*

There is strong evidence to show that housing and accommodation are key drivers of disability costs: disabled people who live in unsuitable accommodation end up having to spend particularly highly on equipment and adaptations, and utility bills (frequently, disabled people have higher utility bills than non-disabled people as a direct result of having to stay warm as part of managing their condition or impairment). There is a strong correlation between suitability of housing and disability-related spending.<sup>23</sup>

*"Housing costs more if you need wheelchair access and due to the lack of accessible housing you usually have to pay for expensive extensions and adaptations."* – respondent to survey, 2010

### *Network of support*

DWP research shows that one of the key uses of DLA is that it is put towards buying presents and gifts to acknowledge help and support from family, friends, neighbours, etc. Being able to acknowledge this support is extremely important to recipients' "sense of reciprocity and dignity".<sup>24</sup> Such gifts and presents are vital to maintaining informal networks of support. Without these, many disabled people are prevented from doing the things they want to do, and leading the lives they value.

*"Very often I have to go hours without hygiene care because there is no one here and I cannot move unaided. I have no social life because there is no one I can ask to take me out."* – survey respondent, 2010

Moreover, social isolation – as well having a detrimental effect on a disabled person's health and wellbeing – also brings with it significant additional disability

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<sup>20</sup> Papworth Trust 'Changes to Disability Living Allowance Survey Results – summary', August 2011, [http://www.papworth.org.uk/downloads/dlasurveyresultssummary\\_110830174513.pdf](http://www.papworth.org.uk/downloads/dlasurveyresultssummary_110830174513.pdf) (accessed September 2011)

<sup>21</sup> Greenhalgh, C & Gore, E *Disability Review 2009* (London: Leonard Cheshire Disability, 2009)

<sup>22</sup> Wood, C & Grant, E *Counting the Cost* (London: Demos, 2010)

<sup>23</sup> Wood, C & Grant, E *Counting the Cost* (London: Demos, 2010)

<sup>24</sup> Corden, A et al, *The impact of Disability Living Allowance and Attendance Allowance: findings from exploratory qualitative research*, DWP Research Report 649 (London: DWP, 2010)

costs. A disabled person or person with mental health conditions who needs help with household maintenance might have to pay for formal help, if there is no-one around who is able to help them (and they are ineligible for social care).

*"I also have to pay for help with cleaning up and taking the rubbish out and vacuuming that I can't do now as Social Services won't give me a care package or direct payments or a personal budget."* Person with mental health condition – survey respondent 2010.

Research by Demos shows that no access to informal support from family and friends is a key driver of additional disability costs.

*"I am therefore having to rely on the goodwill of family-if my family were unable to support me and provide free care I honestly don't know what would happen- what the future will hold I don't know. Any "spare" money I have, I have to save to be able to afford disability related equipment in the future or help my family out when I can to meet some of the extra costs of looking after me."* – survey respondent, 2010

### *Employment status*

DWP research shows that one of the key outcomes of receiving DLA is that it helps recipients stay in employment and maintain contact with the labour market.<sup>25</sup> Disability-related costs vary depending on whether the recipient is in or out of work. For those in employment, DLA is often a vital lifeline of support that helps people to carry out household tasks or help meet family responsibilities that they are unable to conduct after work because of their condition.

*"I know lots of people don't cook nowadays but I rely on ready meals and takeaways a lot because I am not well enough to cook after working all day. I don't have an option and they are expensive. I only have the energy to work and not much else."* – survey respondent, 2010

That DLA is available to people both in and out of work is vital; the Government's decision not to change this with the introduction of PIP is warmly welcomed and must remain the case. However, disability costs are strongly influenced by whether or not the recipient is in work: for example, someone who is at home all day (and this may well be because they work from home rather than because they are unemployed – see above) and, because of their condition has to ensure they stay warm, will have higher utility bills than were they working; a disabled person in work may have to pay for specialist transport (the costs of which might not be met by Access to Work), or, because of their condition, may be so tired after work they are unable to undertake everyday household tasks, play with and look after their children, prepare and cook meals, etc.

We strongly urge the Government to resist any temptation to reduce eligibility for PIP for those who are out of work. And yet, if PIP is designed to serve as a contribution with which recipients can meet some of the extra costs of disability, it is important to take into account whether or not the recipient is in work, as this will affect the barriers they face and the costs they incur.

### *DLA and PIP: a unique position*

DLA occupies a truly unique position in the welfare benefits system – as will its successor PIP – as the only, non-means tested, non-ring-fenced (in that how it is spent is at the recipient's own discretion) benefit, specifically designed to contribute

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<sup>25</sup> Corden, A et al, *The impact of Disability Living Allowance and Attendance Allowance: findings from exploratory qualitative research*, DWP Research Report 649 (London: DWP, 2010)

towards the extra costs of living with an impairment or health condition. Other benefits simply do not occupy the same space, or can be acquired in the same way – even if, in the end, they are put towards similar purposes – as shown by the table below.<sup>26</sup>

<b>Benefit</b>	<b>Purpose</b>	<b>Condition(s) to entitlement</b>
Community Care Grant	To assist people to live independently in the community; ease any financial pressures on family; help with certain travel expenses.	Means-tested (recipient must be receiving an income-based qualifying benefit (e.g. inc.-JSA).
		Cannot be used to cover costs of fuel consumption; costs of improvements to a home; or costs of purchasing, installing a telephone (among other restrictions).
Crisis Loan	Loans for people who are unable to meet immediate needs as a result of emergency, disaster or in particular circumstances.	It is a loan, and so has to be repaid (usually by deductions of another benefit).
		Must need the loan in the case of a disaster or emergency or specific circumstances – not because of disability-related barriers and costs.
		May take savings into account
		Cannot be used to cover costs of mobility needs, holidays, TV or radio, purchase and running of vehicle.
Budgeting Loan	Loans for people to meet intermittent expenses for specified items, which it could be hard to budget for.	It is a loan, and so has to be repaid (usually by deductions from another benefit).
		Means-tested (recipient must be receiving an income-based qualifying benefit (e.g. inc.-JSA).
Disabled Facilities Grant	Designed to help with costs of adapting a property for the needs of a disabled person.	Must be “treated as disabled” (limited definition).
		Disabled Facilities Grants are means-tested for adults.

<sup>26</sup> Benefits information taken from Disability Alliance *Disability Rights Handbook – 36<sup>th</sup> edition: April 2011 – April 2012* (Disability Alliance: London, 2011)

## The abolition of DLA and the introduction of PIP

### Objectives of reform

The Welfare Reform Bill was introduced in February 2011. The Bill makes provision for the abolition of DLA and the introduction of PIP, which will replace it. All current DLA claimants – between the ages of 16 and 64 – will be reassessed should they wish to receive PIP.

The objectives of reform are set out in the Impact Assessment; the plan is intended to:

- Create a new more active and enabling benefit that supports disabled people to overcome the barriers they face to leading full and independent lives;
- Ensure that support is focused on those with the greatest barriers and that expenditure is sustainable; and
- The new assessment is being designed to assess more accurately, objectively and transparently those people who would benefit most from additional support.<sup>27</sup>

The initial draft criteria for the assessment were published in May 2011. The aim of creating a more enabling benefit that supports disabled people overcome the barriers they face to leading full and independent lives is laudable – and to be strongly supported. However, the assessment and the principles underlying it are not fit for purpose. Closer scrutiny of the draft assessment – its principles, activities and proposed descriptors (which, at this point, are still subject to change) shows there are four, serious flaws that, unless rectified, could risk undermining highly positive objectives. These flaws are:

1. **The assessment is highly medical, and not based enough on the social model of disability;**
2. **The assessment will be of limited use in achieving the objectives of reform;**
3. **Aims of achieving an assessment that is both totally ‘objective’ and accurate, and that achieve its original objectives for reform, contradict one another; and**
4. **The criteria against which prospective recipients will be assessed is restricted to the point of being counter to the original purpose of both the new benefit and its predecessor.**

### 1. The test is highly medical and not based enough on the social model of disability

Prior to the introduction of The Welfare Reform Bill, the Minister for Disabled People, Maria Miller MP, asserted that the Government is “absolutely committed to a social model for [DLA reform], not a medical model”.<sup>28</sup> In the DLA reform consultation document, published by the Government in December 2010, it states: the “benefit will continue to take account of the social model of disability”.<sup>29</sup> According to disability activists and academics, the social model of disability “shifts attention away from individuals and their physical or mental deficits to the ways in which society includes

<sup>27</sup> DWP *Disability Living Allowance Reform – Impact Assessment* (London: DWP, 2011)

<sup>28</sup> Miller, M, *Hansard*, 30 Nov 2010, col 220WH,

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101130/halltext/101130h0001.htm#10113030000270> (accessed September 2011)

<sup>29</sup> DWP *Public consultation Disability Living Allowance reform* (The Stationary Office: London, 2010)

or excludes them”.<sup>30</sup> Indeed, the original DLA reform consultation paper outlines the social model too. It says:

*“The social model of disability says that disability is created by barriers in society. These barriers generally fall into three categories:*

- *The environment – including inaccessible buildings and services*
- *People’s attitudes – stereotyping, discrimination and prejudice*
- *Organisational barriers – inflexible policies, practices and procedures.*

*The social model argues that these barriers, unlike most impairments, can be changed or removed: for example physical barriers in the workplace can be removed and attitudes of employers changed so that disabled people no longer face discrimination in the workplace.”<sup>31</sup>*

Elsewhere in the consultation paper, it states

*“We remain committed to the social model of disability. The new assessment will not be based solely on the medical model of disability and focused entirely on an individual’s impairment, but will instead focus on the ability of an individual to carry out a range of key activities necessary for everyday life.”<sup>32</sup>*

However, inspection of the principles, activities and descriptors underlying the assessment criteria shows there to be little to no consideration of the social model of disability. In fact, ‘barriers’ as they are framed in the context of DLA reform are purely centred on a disabled person’s limitations as a result of their impairment or health condition. As made explicit in the initial draft assessment criteria,

*“The assessment will consider an individual’s ability to undertake the activities selected. Inability to undertake activities must be due to a physical, mental or cognitive impairment with disabling effects and not simply a matter of preference by the individual”.<sup>33</sup>*

As shown above, a disabled person’s ability or inability is considered only in regards to the problems that their health condition or impairment cause them; there is nothing to take into account the very real social, practical and environmental barriers that prevent disabled people and people with mental health conditions from exercising choice and control and leading the types of lives they value. The proposed assessment is not broad enough in scope – nor is it designed to be – to consider the wider external barriers that drive up extra costs for disabled people.

Ultimately, while we are in no doubt that people’s impairments and health conditions do give rise to significant barriers that prevent them from doing the things they want to, we strongly believe that an assessment that only focuses on impact of impairment or health condition will only ever show half the real picture. Without paying due consideration to social, practical and environmental barriers – and the extra disability-related costs connected to these, the results from the assessment will only be partly accurate.

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<sup>30</sup> Shakespeare, T *Disability Rights and Wrongs* (London: Routledge, 2006)

<sup>31</sup> DWP *Public consultation Disability Living Allowance reform* (The Stationary Office: London, 2010)

<sup>32</sup> DWP *Public consultation Disability Living Allowance reform* (The Stationary Office: London, 2010)

<sup>33</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

## 2. The assessment will be of limited use in achieving the objectives of reform

The policy objectives underlying DLA Reform and the introduction of PIP are several, but include:

- Supporting “disabled people to overcome the barriers they face to leading full and independent lives”;
- Ensuring that support “is focused on those with the greatest barriers”; and
- Assessing “those people who would benefit most from additional support”.<sup>34</sup>

As noted, DLA – and its soon-to-be successor, PIP – is designed to help contribute towards the additional costs disabled people incur as a result of living with an impairment or health condition. It therefore makes sense that, to be well targeted and of most use to helping the Government achieve its objectives, the assessment for PIP produces an accurate reflection of the barriers disabled people face and the extra costs they incur. However, the initial draft of the assessment criteria retains a restricted focus on whether an individual’s impairment – physical, mental or cognitive – affects their ability to carry out the selected activities – which are themselves extremely limited by focusing mostly on care and mobility.<sup>35</sup> And yet, there is research to show that focusing only on the impact of a person’s impairment, and limiting the arenas in which barriers and extra costs arise, will only show some of the picture as to what barriers that disabled person faces in their everyday lives.<sup>36</sup> Indeed, as previously explained, often, the ‘greatest barriers’ can arise from social, practical and environmental factors like inaccessible public transport, unsuitable housing, and lack of access to informal support from family, friends, neighbours, etc. **Without considering these, the objectives of creating a benefit that “supports disabled people overcome the barriers they face to leading full and independent lives”, and of ensuring “that support is focused on those with the greatest barriers” will remain unachievable.**

Finally, the last objective: that the new assessment “is being designed to assess more accurately, objectively and transparently those people who would benefit most from additional support”. Without considering social, practical and environmental barriers alongside impact of impairment or health condition,<sup>37</sup> the assessment will never be as accurate as it could be, nor will it identify “those people who would benefit most from additional support.” Fundamentally, **focusing only on impact of impairment or a health condition risks targeting PIP not towards “those with the greatest barriers”, but specifically to those with the greatest impact of impairment or health condition. This risks turning PIP into a medical or social care budget by implication – as it suggests that only those whose needs arise directly from the limitations caused by their impairment, and not by society, should be entitled to support. We believe that this risk can be avoided by redesigning the PIP assessment and pathway so that it is based more on the social model of disability, and takes into account the barriers disabled people face that arise beyond care needs.**

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<sup>34</sup> DWP *Disability Living Allowance Reform – Impact Assessment* (London: DWP, 2011)

<sup>35</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

<sup>36</sup> Wood, C & Grant, E *Counting the Cost* (London: Demos, 2010)

<sup>37</sup> (And still, this would be better framed in terms of condition management – how a disabled person or person with a mental health condition manages their impairment or condition, what coping strategies they have in place, etc.)

### **3. Aims of achieving an assessment that is both totally ‘objective’ and accurate, and that achieve its original objectives for reform, contradict one another**

The Government has consistently stressed its desire to devise an ‘objective’ assessment, and yet still come up with a test that is accurate and which targets those who face the greatest barriers. Here we make plain the argument that all three aims cannot be achieved together. While we understand and appreciate the Government’s concerns that a more ‘subjective’ assessment might lead to inconsistency of application, we are concerned that this has been taken as reason to come up with a relatively simplistic approach that will tell the assessor relatively little about how much extra it costs to be a disabled person in our society. Further to this, we would make the following points:

- **No assessment is fully objective** – even one that uses a points-based, descriptor approach like the Work Capability Assessment (which, it should be noted, has been continually subjected to widespread criticism, a high level of appeals overturned in favour of the claimant, and has sparked the need for a four year review process by Professor Harrington) is ultimately down the subjective decisions that are made by the assessor themselves (and then, typically, the DWP/JCP decision-maker).
- **Using *only* a points-based, tick box descriptor approach will not capture enough information about the barriers and costs disabled people face on a daily basis.** Ultimately, this will not allow either the assessor or the DWP decision-maker to make a fully informed decision as to whether or not the individual is entitled to PIP. This will compromise the accuracy of the assessment and the objective of focusing support on those who face the greatest barriers.

### **4. The criteria against which prospective recipients will be assessed is restricted to the point of being counter to the original purpose of both the new benefit and its predecessor.**

Finally, the criteria itself, against which prospective recipients will be assessed, is too limited and by emphasis on the medical model and not accounting enough for social, practical and environmental barriers will render it less accurate and less effective as a means of support that contributes towards the additional costs of living a health condition or impairment.

We do acknowledge and agree that the Government has sought to extend the list of activities assessed from that currently covered by DLA, and that the new mobility and communication-related criteria are steps in the right direction. But, if the Government is sincere about developing “a new more actively and enabling benefit that support disabled people to overcome the barriers they face to leading full and independent lives”, than the activities in the draft criteria do not go far enough. These shall now be looked at in detail.

## The Assessment – analysis

The prospective activities – and the possible weight in terms of the scores attached to them – are outlined below (note: these are taken from DWP documents<sup>38</sup>):

Number	Activity	Scoring
1	Planning and buying food and drink	Medium scoring
2	Preparing and cooking food	Medium scoring
3	Taking nutrition	Medium scoring
4	Managing medication and monitoring health conditions	Low scoring
5	Managing prescribed therapies other than medication	Low scoring
6	Washing, bathing and grooming	Medium scoring
7	Managing toilet needs and incontinence	Medium scoring
8	Dressing and undressing	Medium scoring
9	Communicating with others	High scoring
10	Planning and following a journey	High scoring
11	Getting around	High scoring

The activities are then scored – according to descriptors – on a level from A onwards – as stated: “descriptor D is likely to receive more points than descriptor B but less than descriptor F”<sup>39</sup>. On the other side of the spectrum, “in each activity, descriptor A is likely to attract **zero** points”<sup>40</sup>. That the points as such have not been published at this point, is of little consequence as it is stated that, “when set”, these points are likely to follow the guidelines mentioned here. With this A-F/G format of scoring in mind, analysis now turns the actual activities set out in the draft assessment criteria.

### Activity 1

Activity #	Title	Description
Activity 1	Planning & buying food & drink	<p>This activity considers the mental, intellectual and cognitive ability of individuals to plan and buy food and drink for themselves, including any food or drink necessary for therapeutic diets. It assesses ability to determine what food and drink is reasonably required to sustain themselves, to choose appropriately, to budget and prioritise the money required for purchasing and to purchase food and drink. The descriptors reflect whether support from another person is required to carry out these tasks.</p> <p>We envisage this activity applying to individuals with health conditions and disabilities affecting mental and cognitive function – for example individuals with mental health conditions, learning disabilities, autism and dementia.</p> <p>Physical ability is not considered in this activity, as it is dealt with in other activities – such as in “Getting around”.</p>
Note		<p>Planning means an individual’s ability to determine what food and drink they reasonably require to sustain themselves and to choose appropriately.</p> <p>Buying means an individual’s ability to determine how much money is required to purchase food and drink to sustain themselves, make an assessment of the availability of that money and to make a purchase.</p>

This activity concentrates on two things: an individual’s ability to plan and choose food and drink; and their ability to determine how much money is needed to buy such items. Already it is apparent from the notes that the only barriers considered here are

<sup>38</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

<sup>39</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

<sup>40</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

those arising from an individual's 'mental, intellectual or cognitive ability. The emphasis on the medical model of disability is strong here.

Disabled people will face many barriers to activities associated to planning and buying food and drink. Some of these will indeed be a related directly to the impact their impairment or health condition; but, many others will be external barriers – caused by social, practical and environmental barriers. Reconsidering the Minister's assurances that the Government is "absolutely committed" to a programme of reform for DLA that is underpinned by the social model,<sup>41</sup> it is hard to see how the social model is considered in activity that considers only "the mental, intellectual and cognitive ability of individuals to plan and buy food".

Activity #	Title	Descriptor ( <i>and notes</i> )	Score
Activity 1	Planning & buying food & drink	Can plan and buy food unaided ( <i>Applies to individuals who can plan food and drink without the use of aids and appliances or the assistance of another person.</i> )	A (0)
		Can buy food and drink only with continual prompting ( <i>May apply to individuals who are unable to buy but can plan without support. May apply to conditions such as mild learning disability or moderate depressive illness.</i> )	B
		Can plan food and drink only with continual prompting ( <i>May apply to individuals who can plan only with support. May apply to conditions such as moderate learning disability or moderate dementia.</i> )	C
		Can plan food and drink only continual assistance ( <i>May apply to individuals who can only plan with support. May apply to conditions such as moderate learning disability, severe depressive illness or moderate dementia.</i> )	D

The focus on impairment or condition is apparent here – in the notes and descriptors. And yet, as outlined from the points and examples below (taken from the aforementioned survey of disabled people and parents of disabled children), it is clear that when planning and buying food and drink, disabled people incur significant additional costs from

- **Needing to buy specialist types of food.** These might be pre-prepared, ready meals, or in accordance with specialist dietary requirements, but, frequently cost more to buy:

*"I am unable to cook other than in a microwave so have to pay more on prepared foods"* – survey respondent, 2010

- **Needing to pay for private transport to get to the shops.** Many disabled people incur significant additional costs when shopping to buy such food because public transport is inaccessible (note: mobility-related costs will be addressed later in this paper);

*"I spend as much on taxis as the food I've bought therefore doubling each visit to the shops."* – survey respondent, 2010

- **Needing to get food delivered.** Inaccessible transport, often combined with lack of support from an informal network – meaning there may be nobody

<sup>41</sup> Miller, M, *Hansard*, 30 Nov 2010, col 220WH, <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm101130/halltext/101130h0001.htm#10113030000270> (accessed September 2011)

available to help them, a friend, family member, partner, etc. – means many disabled people have to order food online and get it delivered, which raises disability costs for them.

*“I order food through the internet as I am unable to walk round a supermarket or get to one, this means that I spend more than I want to as there is a minimum you need to spend.” – survey respondent, 2010*

For many disabled people, these barriers are often compounded by not having someone who can help them with this activity on an informal basis. This shows, again, that informal network of support has a strong influence on the additional disability related costs that PIP will be supposed to contribute towards.

*“I don't have family living near me who can help so I often end up paying more for things like food shopping as I have rely on help provided by the stores.” – survey respondent 2010*

- **Needing to pay for extra food and drink for a carer (and this is not covered in a social care plan, or they do not have one).** For disabled people who do have carers, but do not have such provision set out in their social care plan, and particularly for disabled people who receive no social care but rely on informal carers, they often incur extra disability costs from having to pay for food and drink for their carer or support figure.

*“I have a 24/7 care package from social services which is great but it doesn't cover the full costs like my PAs food for instance.” – survey respondent, 2010*

## Activity 2

Activity #	Title	Description
2	Preparing food & drink	<p>This activity considers an individual's ability to prepare either a simple meal or an uncooked snack. This must be due to the impact of a health condition or impairment on ability to perform the tasks required, rather than a reflection of an individual's cooking ability. It assesses ability to open packaging, serve food, pour a drink, peel and chop food and use a microwave oven or cooker hob to cook or heat food. The descriptors reflect the use of aids or appliances and whether support from another person is required to carry out these tasks.</p> <p>We envisage this activity applying to, for example, individuals with arthritis, mental health conditions, visual impairment, epilepsy, learning disabilities, multiple sclerosis and Parkinson's disease.</p>
Note		<p><i>Preparing food means basic preparation, such as peeling and chopping.</i></p> <p><i>Cooking food means cooking or heating - for example, in a microwave oven or on a cooker. This activity assumes that all actions are carried out above waist level. Therefore it does not consider the ability to bend down - for example, to access an oven.</i></p> <p><i>A simple meal is considered a one-course meal for one from either fresh or frozen ingredients.</i></p> <p><i>A snack is considered something that is uncooked and can be easily made with minimal simple preparation, such as a sandwich.</i></p> <p><i>Packaging includes tins, which may require the use of a tin opener.</i></p> <p><i>In this activity aids and appliances includes things like a prosthesis, perching stool, lightweight pots and pans, easy grip handles on utensils and single lever arm taps etc.</i></p> <p><i>Descriptors d – g in particular may also apply to individuals with visual impairment depending on the extent to which they have adapted.</i></p>

Descriptor (and notes)

Score

Can prepare and cook a simple meal unaided.	A (0)
Can prepare and cook a simple meal only with the use of an aid or appliance. <i>(May apply to individuals who can prepare and cook food but need aids and appliances. May apply to conditions such as moderate arthritis.)</i>	B
Can prepare and cook a simple meal only with continual prompting. <i>(May apply to individuals with conditions such as moderate/severe depressive illness with lack of motivation, psychotic disorders and moderate/severe learning disability where there is a need for them to be prompted to complete the task. This could also include someone with visual impairment who, amongst other things, is unable to ascertain if food is within date)</i>	C
Can cook a simple meal using a conventional cooker only with continual assistance. <i>(May apply to individuals who cannot use a hob, either because of cognitive or mental health conditions or an upper limb disorder, which prevents them from safely using hot pans but could still microwave a meal. It may also apply to someone with epilepsy who has regular fits and is unable to safely use a hob.)</i>	D
Can prepare a simple meal for cooking only with continual assistance. <i>(May apply to individuals who cannot prepare food because of, for example, moderately reduced manual dexterity due to conditions such as rheumatoid arthritis or Parkinson's disease.)</i>	E
Can cook a simple meal using a microwave only with continual assistance. <i>(Notes: may apply to individuals who cannot heat food without assistance - for example, because of a lack of awareness of danger, such as those with a severe learning disability.)</i>	F
Can prepare a simple snack only with continual assistance. <i>(May apply to individuals who cannot complete the task. May apply to conditions such as severe learning disability, severe psychotic illness, advanced multiple sclerosis or severe rheumatoid arthritis.)</i>	G

Again, here the sole focus on impact of impairment is explicit; the descriptors centre purely on impact of impairment or health condition. For many disabled people, their impairment or health condition will cause them significant problems to preparing food and drink. However, evidence shows that barriers to this activity are also external – and could come in the form of unsuitable housing for instance. And yet, **a disabled person whose ability to prepare food and drink is impeded not by their impairment or condition but due to an external factor like unsuitable housing could well be likely to score A (0 points) as their impairment does not prevent them from preparing and cooking a simple meal unaided.** This compromises the accuracy of the test.

*“I don't have enough money to make my home wheelchair accessible nor can I afford to fund adaptations in my kitchen therefore I cannot reach the side to cook/prepare food.”*  
– survey respondent, 2010

Furthermore, the fact that the descriptors do not consider the suitability of a disabled person's home and *also* do not consider “the ability to bend down – for example, to reach an oven” means that disabled people who are seen to be able to prepare and cook a meal but may not be able to do so because of their housing situation, would be likely to score A – despite perhaps being among “those people who would benefit most from additional support”.<sup>42</sup>

*“I receive very little support from the local authority, even though they moved me as a priority due to disability and being flat-bound - they moved me into a shared ownership terraced house with bedroom & toilet upstairs, no toilet downstairs, no access for my wheelchair in the house and no access to the kitchen or garden. I applied and was awarded a Disabled Facilities Grant but this was never actioned by the Local Authority to build an accessible kitchen and downstairs toilet.”* – survey respondent, 2010

**Nor do the descriptors take into account other vital factors: such as whether the disabled person has familial responsibilities. A disabled person or an individual with mental health conditions may be able to ‘prepare and cook a**

<sup>42</sup> DWP *Disability Living Allowance Reform – Impact Assessment* (London: DWP, 2011)

**simple meal unaided', but may struggle to cook three meals a day for a family. A single disabled parent could well be in this position.**

### Activity 3

Activity #	Title	Description
Activity 3	Taking nutrition	This activity assesses ability to be nourished, either by cutting food into pieces, conveying to the mouth, chewing and swallowing or through the use of therapeutic sources. The descriptors reflect the use of aids or appliances and whether support from another person is required to carry out these tasks.  We envisage this activity applying to, for example, individuals with arthritis, dementia, neurological conditions, and those who require enteral and parenteral feeding.
Note	<i>A therapeutic source means parenteral or enteral tube feeding using a rate-limiting device such as a delivery system or feed pump.</i>	

Descriptor (and notes)	Score
Can take nutrition unaided.	A (0)
Can take nutrition only with the use of an aid or appliance. <i>(May apply to individuals who require aids and appliances. May apply to conditions such as arthritis.)</i>	B
Can take nutrition only with the use of a therapeutic source. <i>(May apply to individuals who require enteral or parenteral feeding but can do so unaided.)</i>	C
Can take nutrition only with intermittent assistance or prompting. <i>(May apply to individuals who need another person to be present intermittently whilst feeding. This may apply to individuals who can only finger feed, those with dementia who need to be reminded to eat and individuals with visual impairment. Eating disorders are unlikely to be apply here - however, functional effects from a severe eating disorder may lead to inability to complete descriptors in a number of other activities.)</i>	D
Can take nutrition only with the use of a therapeutic source and with intermittent assistance. <i>(Support may be required to set up or monitor the equipment. May apply to individuals who require enteral or parenteral feeding and require support to manage the equipment. May apply to conditions such as disabling neurological conditions.)</i>	E
Can take nutrition only with continual assistance. <i>(May apply to individuals who need to be fed by someone else. May apply to conditions such as severe neurological conditions, profound or severe learning disability or low functioning autism.)</i>	F

This activity focuses, like the others, on an individual's ability, or rather inability, as result of "a physical, mental or cognitive impairment with disabling effects" to eat.<sup>43</sup> Considering the barriers already mentioned that may inhibit a disabled person's capability to acquire and to prepare food in the first place, by the point of eating many disabled people will already have faced significant barriers and incurred additional costs – from having to pay for specialist or pre-prepared food; having to pay online delivery charges, or pay for a carer (formal or informal) or friend to go out and buy it on their behalf; and then may have had to pay for someone to help them prepare and cook it – not because their impairment or condition inhibits them, but because their home is not suited to their needs.

**Even in the limited arena of buying, preparing, cooking and eating a meal, there are a raft of barriers and additional costs a disabled person could incur that are not solely down to their physical, cognitive or mental ability. Because of this, the assessment has serious consequences for the Government's**

<sup>43</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

**objective of creating a benefit that supports disabled people to overcome the barriers they face to leading full and independent lives.**

### Activity 4

Activity #	Title	Description
Activity 4	Managing medication & monitoring health conditions	This activity considers an individual's ability to take prescribed medication at the right time and to monitor and detect changes in a health condition, without which their health is likely to significantly deteriorate. The descriptors assess whether support from another person is required to carry out these tasks and the frequency per day of such support. Examples of prescribed medication include tablets, inhalers and creams. We envisage this activity applying to, for example, cognitive impairments, mental health conditions and upper limb disorders.
<b>Notes</b>	<p>This activity does not take into account medication and monitoring provided by a healthcare professional.</p> <p>Managing medication means the ability to take prescribed medication at the right time. Examples of prescribed treatment include tablets, inhalers, nasal sprays and creams.</p> <p>Monitoring a health condition or recognise significant changes means the ability to detect changes in the condition and take corrective action as advised by a healthcare professional, without which the person's health is likely to significantly deteriorate.</p> <p>The descriptors refer to the frequency of support required, for example, the dosing regime.</p> <p>Monitoring health condition will include individuals whose condition may significantly deteriorate in the short term if not adequately monitored, for example monitoring blood sugar levels in an insulin dependent diabetic.</p> <p>The ability to convey tablets to the mouth is captured in the descriptors for 'Taking nutrition' and therefore no separate descriptor is included here.</p> <p>Supervision due to the risk of accidental or deliberate overdose or deliberate self-harm is captured in these descriptors as the person would require support from another person in order to prevent this. Aids, such as dosette boxes, are included in any consideration of ability to carry out the task. The descriptors are therefore only looking at whether assistance or prompting from another <b>person</b> is required.</p>	

Descriptor (and notes)	Score
Does not receive medication or need to monitor a health condition <b>or</b> can manage medication and monitor a health condition unaided or with the use of an aid or appliance.	A <b>(0)</b>
Less than once a day, requires continual assistance or prompting to manage medication <b>or</b> monitor a health condition.	B
Once a day, requires continual assistance or prompting to manage medication <b>or</b> monitor a health condition.	C
Twice a day, requires continual assistance or prompting to manage medication <b>or</b> monitor a health condition.	D
At least three times a day, requires continual assistance or prompting to manage medication <b>or</b> monitor a health condition.	E

The focus here is on an individual's ability – as affected by their impairment or condition. Yet the narrow focus will show only part of the picture of the barriers and extra disability costs a disabled person may face when managing their condition. A disabled person – someone who may well be able to “take prescribed medication at the right time”, “detect changes in their condition and take corrective action” unaided or with the use of an aid or appliance would score A, and most likely zero points – could still face significant barriers and disability-related costs as a result of external factors that this test does not begin to capture.

- **'Prescribed' medication is a key source of disability-related costs.** The framing of this activity allows no consideration of the reality that many disabled

people have to pay for their prescriptions, which often come at considerable costs that often impact on their ability to manage their condition.

*“[I] lost middle rate DLA and therefore lost IS so had to pay for prescriptions and not able to pay for therapy.” – survey respondent 2010,*

*“Autistic people have unusual pharmacokinetics so we don't necessarily respond well to medications that work for non-autistic people and one of the only medications that works for me is blacklisted by NICE so I have to pay privately as can't function without it. The other I pay privately for as it is not licenced in UK for my condition even though it is in US, so have to get it privately.” – survey respondent, 2010*

While there are systems in place to help people on low incomes receive support for prescriptions, many of these are means-tested. People who would meet the criteria for DLA and PIP, but would not meet the means-testing requirement, will have to pay out significant amounts of their income to pay for prescriptions that are not free. In order for such costs not to become a barrier to leading a full life, it is important that the assessment for PIP considers this.

- **A disabled person may well be able to “manage medication and monitor a health condition...with the use of an aid or appliance”, and score zero points, but will have incurred significant disability costs from the purchase, running and maintenance of such aids and appliances.** In the draft criteria, it says that the assessment will take some account of aids and appliances that an individual uses in their everyday lives. “We recognise that some aids or appliances can help an individual but also attract significant on-going costs. We have attempted to reflect this in the detail of the descriptors and will also seek to do so in the points scores associated with these.”<sup>44</sup> And yet, it is clear looking at the draft descriptor for A, that a disabled person who incurred disability costs due to buying and using aids and appliances to help them manage their health condition could score zero, and possibly receive no support.

**The extra costs of disability equipment are clearly not considered here.** Yet, we know from research that such equipment is often not provided on the NHS and, due to a dearth of suppliers, can cost large sums of money, which can then impact on a disabled person's disposable income. In the aforementioned survey by the Papworth trust, over a third of disabled people receiving DLA used it to pay for specialist equipment.<sup>45</sup> Given below are examples from the ComRes survey, carried out on behalf of Scope.

*“I also have an oxygen concentrator which I get some money back from the Oxygen service but it still costs money to run.” – survey respondent, 2010*

*“All specialty disability related items are expensive - both because of small sales and because of lack of choices - e.g. anything to do with wheelchair, mobility aids, special clothing for wheelchair.” – survey respondent, 2010*

Finally, running and charging such equipment – for example, an electric wheelchair – could mean the disabled person incurs significant disability-related costs as result. Aforementioned research by Demos showed that disabled people have higher spending on utilities like electric, often because they have to run

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<sup>44</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

<sup>45</sup> Papworth Trust 'Changes to Disability Living Allowance Survey Results – summary', August 2011, [http://www.papworth.org.uk/downloads/dlasurveyresultssummary\\_110830174513.pdf](http://www.papworth.org.uk/downloads/dlasurveyresultssummary_110830174513.pdf) (accessed September 2011)

equipment. The Papworth Trust's recent survey showed that more than half of disabled people used their DLA to pay for utility bills.<sup>46</sup>

## Activity 5

Activity #	Title	Description
Activity 5	Managing prescribed therapies other than medication	This activity seeks to identify an individual's ability to manage long-term non-pharmaceutical, prescribed home therapeutic activities, without which their health is likely to significantly deteriorate. The descriptors assess whether support from another person is required to carry out these tasks and if so, the duration of such support. This varies according to the type of procedure undertaken. Examples of prescribed therapies include home oxygen, domiciliary dialysis, nebulisers and exercise regimes to prevent complications such as contractures and without which the person's health is likely to significantly deteriorate.  We envisage this activity applying to, for example, individuals with cognitive impairments, mental health conditions and lower and upper limb disorders.
Notes	<i>This activity does not take into account assistance with prescribed home therapies from a healthcare professional. This activity does not include management of incontinence as it is covered under activity 7. The duration of support varies according to the type of procedure</i>	

Descriptor (and notes)	Score
Either is not prescribed therapies <b>or</b> can manage prescribed therapies unaided.	A (0)
Where prescribed therapies are required for up to 3.5 hours a week, can manage only with intermittent assistance.	B
Where prescribed therapies are required between 3.5 and 7 hours a week, can manage only with intermittent assistance.	C
Where prescribed therapies are required between 7 and 14 hours a week, can manage only with intermittent assistance.	D
Where prescribed therapies are required at least 14 hours a week, can manage only with intermittent assistance.	E

Here, the ability of disabled person or person with a mental health condition to manage their condition is considered in regards to how they "manage long-term non-pharmaceutical prescribed home therapeutic activities", such as "home oxygen, domiciliary dialysis, nebulisers and exercise regimes'. However, once again, analysis shows there to be other barriers, besides those related directly to what a person's impairment or condition prevents them from doing, that are not captured here, and yet could still compromise a disabled person's capability to exercise choice and control, and be independent. These are:

- **Many 'prescription' therapies are only prescribed in the short-term.** Here the terms 'long-term' and 'prescribed' often run counter to one another as many prescribed therapies are only available for a short space of time. After this, the disabled person has to pay for it themselves, as well as the costs of travel (which may have to be hired privately), carer or friend to accompany them, etc.

*"My NHS physiotherapist said I should have weekly massage therapy and I found it very effective. However the NHS would only provide 6 weeks. Good massage therapy is expensive and as such I have never been able to afford it as anything other than an occasional treat."* – survey respondent, 2010

- **Many therapies disabled people and people with mental health conditions require in order to manage their conditions are *not* available on prescription or in the home.** Disabled people are best placed to know how to

<sup>46</sup> Papworth Trust 'Changes to Disability Living Allowance Survey Results – summary', August 2011, [http://www.papworth.org.uk/downloads/dlasurveyresultssummary\\_110830174513.pdf](http://www.papworth.org.uk/downloads/dlasurveyresultssummary_110830174513.pdf) (accessed September 2011)

manage their condition on a day-to-day basis. For many, doing so will require them to undertake activities falling outside the remit of ‘long-term prescribed home therapies’, and yet being unable to do these – often because of barriers and disability costs – will make their condition or impairment worse.

*“Hypnotherapy controls depression, but again is not available on NHS” – survey respondent, 2010*

*“I would require special massages and therapy for my muscles that I wouldn’t get on the NHS.” – survey respondent, 2010*

*“The local swimming pool is not accessible to her so we have to pay £20 a session plus fuel costs to take her swimming each week to a hydrotherapy pool with suitable hoist equipment. If she had more money she would go swimming more often as this is what she really enjoys - she has freedom from her wheelchair then.” – parent of disabled child, survey respondent, 2010*

**This activity and the descriptors around are clearly very much centred on the medical model of disability – restricted to therapies prescribed by doctors and healthcare professionals, with little recognition of the fact that disabled people and people with mental health conditions are often placed to decide what therapies and activities are the best means of managing their condition.**

## Activity 6

Activity #	Title	Description
Activity 6	Washing, bathing and grooming	This activity assesses ability to clean one’s face, hands, underarms and torso, to brush teeth and to brush and wash hair, to a level which is socially acceptable and not damaging to one’s personal health. The descriptors reflect the use of aids or appliances and whether support from another person is required to carry out these tasks.  We envisage this activity applying to, for example, individuals with lower and upper limb impairments, cognitive impairments and mental health conditions.
Notes	<p><i>Bathing is the ability to clean one’s face, hands, underarms and torso (the body excluding the head, neck, perineum and limbs), above a level of self neglect (to the extent of being socially acceptable), using a suitable bath or shower.</i></p> <p><i>Washing is the ability to clean one’s face, hands and underarms above a level of self-neglect. It does not include cleaning the torso and limbs.</i></p> <p><i>Grooming means the ability to brush teeth, comb/brush and wash hair above a level of self-neglect.</i></p> <p><i>The activities required to brush teeth and reach up to the head to brush/wash hair are similar to those required to shave. Therefore, this activity is not explicitly included in the definition of grooming.</i></p> <p><i>Cultural differences are reflected in this activity insofar as the skills required to complete the tasks are cross cultural.</i></p> <p><i>This activity excludes cleaning the perineum since this is covered under activity 7.</i></p>	

Descriptor (and notes)	Score
Can wash, bathe and groom unaided.	A (0)
Can bathe unaided but can groom only with the use of an aid or appliance. (May apply to individuals with moderate upper limb impairment affecting both manual dexterity and reaching. Suitable aids could include items such as modified hair brushes, combs and mirrors.)	B
Can bathe unaided but can groom only with continual assistance. (May apply to individuals with moderate upper limb impairment affecting both manual dexterity and reaching who are unable to make use of aids.)	C
Can wash unaided but can bathe only with the use of an aid or appliance. (Likely to predominantly apply to individuals with moderate lower limb impairments who, for example, cannot either get into the bath or	D

<i>shower or remain standing without suitable aids or appliances, such as a walk in shower or bath/shower seat.)</i>	
<i>Can wash unaided but can bathe only with continual prompting. (May apply to individuals with moderate/severe cognitive or mental health conditions such as depressive illness with lack of motivation and psychotic disorders.)</i>	E
<i>Can wash unaided but can bathe only with continual assistance. (Likely to predominantly apply to individuals with moderate to severe upper limb impairment.)</i>	F
<i>Can wash, bathe and groom only with continual assistance. (May apply to conditions such as severe mental or cognitive impairment or severe upper limb impairment.)</i>	G

- Choice and control should mean self-respect, not just “a level above self-neglect.”** In the Government’s response to the consultation on DLA Reform, which was published after the decision to abolish DLA and introduce PIP had already been enshrined in the Welfare Reform Bill, it states: “The Coalition Government is committed to supporting disabled people to exercise choice and control, and lead active, independent lives.”<sup>47</sup> However, this is clearly not embodied in this part of the assessment, which concentrates only on whether a person’s impairment or condition limits their ability to bathe, wash and groom “above a level of self-neglect.”

As with anyone else, maintaining one’s appearance to a level of *self-respect* – as opposed to simply above self-neglect – is of paramount importance to many disabled people but there are often significant disability-related costs, caused by living with an impairment or health condition, to achieving this. For example, cutting toenails and looking after one’s feet (which is not included in the criteria for grooming) is something most non-disabled people take for granted, but many people with impairments or conditions – especially people who live alone or who have no-one to assist them – have to pay to have this done professionally.

*“I have to pay for a pedicure once a month to look after my feet because I can’t reach them and the carer can’t do it for me (against agency rules).” – survey respondent, 2010*

- For many disabled people, barriers to washing, bathing and groom are not because of their impairment or condition, but because of unsuitable housing – whether or not they can access the bathroom, etc.** For many disabled people, living in unsuitable housing – be this the layout of the home itself or having bath or shower room that is not designed to meet their needs – can be a barrier to washing, bathing and grooming and maintaining one’s appearance. As research shows, the suitability of housing has a direct effect on a disabled person’s extra costs, and so should be considered here if PIP is to be targeted so that it achieves the objectives underlying its introduction.

*“I need mixer taps with a shower fitting on my bath so that I can wash my hair more than once every couple of months or instead of having to go to the hairdressers” – survey respondent, 2010*

*“I struggle getting in and out of the bath and our disability grant for a downstairs shower room was denied due a reduction in government funding (it may or may not be approved at a later date, we just have to ‘wait and see’).” – survey respondent, 2010*

- Many disabled people incur higher costs because they have to wash and bathe more as part of managing their condition.** This inevitably means that

<sup>47</sup> DWP Government’s response to the consultation on Disability Living Allowance reform, April 2011, <http://www.dwp.gov.uk/docs/dla-reform-response.pdf> (accessed September 2011)

many disabled people have to pay considerable amounts of money on utility bills; the Papworth Trust's survey of disabled people showed that 52% spent their DLA on utility bills. Furthermore, it was shown by the research by Demos that disabled people living in unsuitable housing spend more on, among other things, home adaptations and utility bills.<sup>48</sup> Higher utility bills as a result of having to manage a health condition or impairment – in this case, the result of having to run more showers and baths – can have a direct impact on a disabled person's disposable income.

*"I have to take a shower twice daily, and it takes me approx. 20 mins. This is a long time to have a 9kw elec. shower running. If I get cold I cannot move, and this can become dangerous because it can lead to me not being able to breathe."* – survey respondent, 2010.

## Activity 7

Activity #	Title	Description
Activity 7	Managing toilet needs or incontinence	<p>This activity considers an individual's ability to get on and off the toilet, to clean afterwards and to manage evacuation of the bladder and/or bowel, including the use of collective devices.</p> <p>For the purposes of this activity, individuals with catheters and collecting devices are considered incontinent. The descriptors reflect the use of aids or appliances and whether support from another person is required to carry out these tasks.</p> <p>We envisage this activity applying to, for example, individuals with lower and upper limb impairments, neurological conditions, mental health conditions and cognitive impairments.</p>
Notes	<p><i>Toilet needs means the ability to get on and off the toilet and clean oneself afterwards, including self-catheterisation.</i></p> <p><i>Managing incontinence means the ability to manage evacuation of the bladder and/or bowel including using collecting devices but does not include washing self and changing clothes.</i></p> <p><i>Individuals with catheters and collecting devices are considered incontinent for the purposes of this activity.</i></p> <p><i>For individuals with a stoma the relevant area to clean may not be the perineum. Therefore, a broader definition of cleaning oneself (which covers the relevant area) is used above instead of perineum.</i></p> <p><i>The activities required to manage menstruation are similar to those required to manage toilet needs or incontinence. Therefore, this activity is not explicitly included in the definition above.</i></p>	

Descriptor (and notes)	Score
Can manage toilet needs or incontinence unaided.	A (0)
Can manage toilet needs or incontinence only with the use of an aid or appliance. (Relevant aids could include commodes, raised toilet seats, bottom wipers or bidets. May apply to individuals who are not incontinent but who have conditions such as moderate upper or lower limb impairment.)	B
Can manage toilet needs only with continual assistance. (May apply to individuals who are not incontinent but who have conditions such as severe mental or cognitive impairment or severe upper limb impairment. People with neurological problems who are unable to defecate/pass urine unaided may satisfy this descriptor.)	C
Can manage incontinence of either bladder <b>or</b> bowel only with continual assistance. (May apply to individuals who are incontinent of either bladder or bowel.)	D
Can manage incontinence of both bladder <b>and</b> bowel only with continual assistance. (May apply to individuals who are incontinent of bladder and bowel and unable to manage this (including the use of collecting devices) without support. May apply to conditions such as severe mental or cognitive impairment or severe upper limb impairment.)	E

<sup>48</sup> Wood, C & Grant, E *Counting the Cost* (London: Demos, 2010)

Here the activity and descriptors centre upon how a disabled person's health condition or impairment impacts upon their ability to attend to toilet needs or incontinence problems. While it is true that many disabled people will need varying degrees of help and assistance here, the focus only on the medical model and impact of impairment or condition means that other barriers will not be highlighted, but these could still have a detrimental impact on disabled people's ability to exercise choice and control, and to lead full and independent lives.

- **Unsuitable housing can be a significant barrier to attending to toilet needs.** For many disabled people, inaccessible or inappropriate housing serves to further compound impairment or health condition-related problems with attending to toilet needs or managing incontinence.

*"I receive very little support from the local authority, even though they moved me as a priority due to disability and being flat-bound - they moved me into a shared ownership terraced house with bedroom and toilet upstairs, no toilet downstairs, no access for my wheelchair in the house and no access to the kitchen or garden. I applied and was awarded a Disabled Facilities Grant but this was never actioned by the Local Authority to build an accessible kitchen and downstairs toilet. I have been forced to use a bottle and bucket downstairs and have spent more nights sleeping downstairs because I have not been able to make it upstairs."* – survey respondent, 2010

- **Incontinence brings with it extra costs: specialist items and higher utility bills.** By focusing solely on impairment-related factors, this part of the assessment will fail to capture other barriers that give rise to disability-related costs: namely,
  - Having to pay more for 'specialist' incontinence products, and
  - Having to meet higher utility bills as a result of increased washing.

While descriptor (b) does include use of aids or an appliance, this appears to be only in considering how they are *used* in the act of actually meeting toilet needs ("managing incontinence means the ability to manage evacuation of the bladder and/or bowel including using collecting devices but does not include washing self and changing clothes"); yet, **the purchase and maintenance of these products can still have a notable impact on a disabled person's disposable income.**

*"Thongs [sic] cost a lot more e.g. laundry and electricity due to incontinence."* – survey respondent 2010

*"Why are incontinence products so much more money than feminine hygiene products when they are essentially the same materials?"* – survey respondent 2010

*"I think life is definitely more expensive as a disabled person – especially when essential expenses for us can include things such as incontinence pads"* – survey respondent 2010

*"Our heating bills are greater as he gets cold very quickly. In the depths of winter we have to leave the heating on 24hours a day. He creates a lot of washing as he is incontinent."* – survey respondent 2010

*"I end up paying a lot more for bills because as well as being incontinent (gas and water bill increase)."* – survey respondent 2010

## Activity 8

Activity #	Title	Description
Activity 8	Dressing & undressing	This activity assesses an individual's ability to appropriately select, put on and take off culturally appropriate and un-adapted clothing, which may include the need for fastening such as zips or buttons. The descriptors reflect the use of aids or appliances and whether support from another person is required.  We envisage this activity applying to, for example, individuals with lower and upper limb impairments, spinal impairments, rheumatoid arthritis, mental health conditions, cognitive impairments, learning disabilities and autistic spectrum disorders.
Notes	<i>This activity does not include putting on a tie or tying shoelaces.</i>	

Descriptor (and notes)	Score
Can dress and undress unaided.	A (0)
Can dress and undress only with the use of an aid or appliance. ( <i>Aids could include modified buttons, zips, front fastening bras, trouser, Velcro fastenings and shoe aids. May apply to conditions that result in moderate upper, lower limb or spinal impairment - for example, generalised arthritis.</i> )	B
Can dress and undress unaided but can only select clothing appropriate for the environment or dress in the correct order with intermittent prompting. ( <i>Includes a consideration of whether the individual can determine what is appropriate for the environment, such as day/night and the weather, and therefore may apply to conditions that result in moderate mental or cognitive impairment.</i> )	C
Can dress and undress lower body only with intermittent assistance. ( <i>May apply to conditions that result in severe lower limb and spinal impairment.</i> )	D
Can dress and undress unaided but cannot determine appropriate circumstances for remaining clothed. ( <i>May apply to conditions that result in disinhibited behavior.</i> )	E
Can dress and undress upper body only with intermittent assistance. ( <i>May apply to conditions that result in severe upper limb impairment - for example, advanced rheumatoid arthritis.</i> )	F
Can dress and undress only with continual assistance. ( <i>May apply to conditions such as severe mental or cognitive impairment or severe upper and lower limb impairment.</i> )	G

The only barriers considered here arise from how the person's condition or impairment inhibits their ability to do something – in this case, dressing and undressing. For many disabled people, barriers to undertaking this activity stem directly from their impairment. Yet, for many others, barriers and additional costs arise from other factors, for example:

- Having to buy more expensive, 'specialist' items of clothing; or
- Having to buy clothes more frequently because of excessive wear or tear.

Both these factors can have a considerable impact on a disabled person or disabled family's disposable income. Despite being obvious barriers to exercising choice and control, independence and participation, they are not captured here in this part of the assessment (or anywhere else in the test).

*"I work. I need to wear suits. I use a wheelchair that seems to eat suit jackets. I need to regularly buy new suits more often than most. Similarly shoes: they get scraped off everything."* – survey respondent, 2010

*"I spend a lot of time in nightwear as clothing is too restrictive or gets torn or wears away much quicker due to how much they need to be washed."* – survey respondent, 2010

## Activity 9

Activity #	Title	Description
Activity 9	Communicating with others	This activity seeks to identify an individual's ability to engage socially, convey information to and understand other people. The impact of overwhelming psychological distress and uncontrollable behaviour is taken into account and the descriptors distinguish between ability to convey a wish and a basic need. The descriptors reflect the use of aids or appliances and whether support from a trained individual is required, such as a sign language interpreter or lip-speaker.

		We envisage this activity applying to, for example, individuals with learning disabilities, sensory impairments, mental health conditions, learning disabilities and autistic spectrum disorders.
Notes	<p><i>This activity only takes into account communication barriers caused by a health condition or disability – it does not take into account language ability or barriers more generally. For example, a lack of understanding of the English language is not taken into account.</i></p> <p><i>Engage socially means to interact with others in a contextually and socially appropriate manner, understand body language and establish relationships.</i></p> <p><i>Communication support means either support from a person trained to communicate with people with limited communication abilities - for example, lip speakers - or from appropriate aids or appliances.</i></p> <p><i>A simple instruction could be to move out of the way to avoid a hazard. A basic need could be asking for food or help with an activity of daily living like going to the toilet. It may apply to conditions such as severe/profound learning disability or severe organic brain disorder.</i></p> <p><i>Communicating/understanding a choice means exchanging thoughts and ideas by any means. This involves a higher level of ability than understanding a simple instruction or conveying a basic need.</i></p> <p><i>Communication and social engagement cover a wide range of activities, beyond what is considered here, such as reading/accessing information. This is not included as the related impairments are reflected in a number of other activity areas such as 'preparing and cooking food and drink'; 'dressing and undressing'; and 'planning and following a journey'.</i></p> <p><i>This activity may include people who are deaf blind. The descriptor applied will be dictated by the extent to which the person has adapted.</i></p>	

Descriptor (and notes)	Score
Can communicate with others unaided.	A (0)
Can communicate only with communication support (may apply in conditions such as severe/profound deafness.)	B
Cannot, even with communication support, understand or convey a choice to an unfamiliar person. (May apply in conditions such as severe learning disability or moderately severe organic brain disorder.)	C
Cannot engage socially with other people due to such engagement causing either- i. Overwhelming psychological distress to the claimant; or ii. The claimant to exhibit uncontrollable episodes of behaviour that would result in substantial risk of significant distress to the claimant or another person. (There must be evidence of a severe health condition, such as severe autism, learning disability or a mental health condition such as psychotic illness. The level of distress must be so severe that the individual cannot manage day to day activities for several hours afterwards.)	D
Cannot, even with communication support, understand or convey a choice to a familiar person.	E
Cannot, even with communication support, understand a simple verbal or non-verbal instruction or warning from another person.	F
Cannot, even with communication support, convey a basic need by either verbal or non-verbal means.	G

Arguably, the scope of this activity is broader than some of the others that precede it. That it seeks to capture difficulties with exchanging thoughts and ideas, and not just communicate a basic need like needing to go to the toilet, is welcome. But still, **assessing the barriers that a disabled person faces in communicating with others in this way will only show part of the picture.** That this part of the assessment does not take into account activities such as reading or accessing information because it is thought that such barriers related to this will be sufficiently captured in the parts of the assessment that measure whether the recipient can 'plan a journey', read food prices and sell-by dates, and choose appropriate clothing is totally inadequate if the purpose of PIP is to support "disabled people to overcome the barriers they face to leading full and independent lives". In addition to this, there are several other flaws that are worth highlighting here:

- **The barriers – and additional costs – of obtaining and maintaining devices used to enable communication (that is, "an individual's ability to engage**

**socially, convey information to and understand other people”) are not considered.** The assessment is simply designed to measure an individual’s ability in terms of their “physical, mental or cognitive impairment.”<sup>49</sup> However, many disabled people incur significant disability costs as a result of buying communication-related equipment.

*“Have to save for a specialist communications aid to replace the one I use at present when it eventually ceases to work. No money is provided for this by any Government [sic] agency.” – survey respondent, 2010*

*“I also have lots of equipment to enable me to do things like this, a braille display, Jaws for windows, Dragon Naturally speaking, this is just some of the equipment I have that costs money to buy and to run, it costs a fortune in electricity... I have lots of disability products that have to be maintained and cared for, such as my Brailnote which enables me to access the Internet, it cost a lot of money to buy and a fortune if it becomes damaged or broken.” – survey respondent, 2010*

- **The barriers – and additional costs – of accessing related help such as speech and language therapies, which could help improve and maintain some disabled people’s capabilities to communicate, but which are often not provided by the local authority or may be in short supply**

*“If we had more money we would use it for extra therapies to help our child develop and communicate - speech and language therapy in particular as we really struggle to get access to that at school and it is written in our child’s statement, but SLT therapist are in short supply.” – survey respondent, 2010*

## Activities 10 and 11

For the purpose of analysis, these next two activities, and their respective draft descriptors, are considered together, as both relate to assessing the ability of a disabled person or an individual with a mental health condition to get around.

Activity #	Title	Description
Activity 10	Planning and following a journey	<p>This activity is meant to assess the impact of impaired cognitive or mental function and/or visual or hearing impairment on ability to get around. It considers the impact of a mental or cognitive function impairment on an individual’s ability to work out and follow a route for a journey. The descriptors take account of the impact of psychological distress and reflect whether support from another person is required to enable an individual to follow a journey.</p> <p>We envisage this activity applying to, for example, individuals with mental health conditions, learning disabilities, cognitive impairments and visual or hearing impairments.</p>
Notes		<p><i>Planning means the ability to work out a route for a journey. Following means the ability to safely (without harm to self or others) follow a pre-planned route.</i></p> <p><i>Simple journey means travel to a familiar destination that requires walking and/or a single mode of transport such as a bus. Complex journey means travel to an unfamiliar destination that requires a combination of modes of transport (such as a bus and a train).</i></p> <p><i>It is easier, in terms of cognitive and mental function, to use a single mode of public transport such as a single bus rather than multiple modes such as a bus then a train.</i></p> <p><i>It is easier, in terms of cognitive and mental function, to get to familiar than unfamiliar destinations – the complexity of the journey is more important than the distance travelled.</i></p> <p><i>Guide dogs are not considered aids or appliances. They may, however, help an individual to follow a</i></p>

<sup>49</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

<p><i>journey safely and reliably.</i></p> <p><i>For those descriptors, which refer to overwhelming psychological distress, there must be evidence of an enduring mental health condition. The level of distress must be so severe that the individual cannot manage day-to-day activities for several hours afterwards. There must be evidence that overwhelming distress has/would occur, not just that it might.</i></p> <p><i>Safety and reliability are particularly important considerations here if there would be a substantial risk to the individual or others if they went out alone.</i></p>
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Descriptor (and notes)	Score
Can plan and follow a complex journey unaided.	A (0)
Cannot follow any journey alone due to such a journey causing overwhelming psychological distress to the claimant. (May apply to individuals with severe anxiety disorders who are only able to leave the home when accompanied by another person on every occasion. If the person is able to leave the home on any occasion without another person then this descriptor is not satisfied.)	B
Can follow a complex journey only- <ul style="list-style-type: none"> <li>i. If it has been planned by another person; or</li> <li>ii. With continual prompting or intermittent assistance.</li> </ul> <p>(May apply to individuals with moderate learning disabilities, cognitive impairments or severe visual impairments (depending upon the extent to which they have adapted to their impairment). If someone was unable to read English due to a health condition, this descriptor may apply. It may also apply in cases where an individual is unable to ask for directions whilst travelling due to a health condition.)</p>	C
Cannot follow any journey due to such a journey causing overwhelming psychological distress to the individual. (May apply to individuals with severe anxiety disorders who are unable to leave the home at all.)	D
Can follow a simple journey only- <ul style="list-style-type: none"> <li>i. If the journey has been planned by another person; or</li> <li>ii. With continual prompting or intermittent assistance from another person.</li> </ul> <p>(May apply to individuals with severe learning disability, cognitive impairment or severe visual impairment (who have not adapted to their impairment).</p>	E

Activity #	Title	Description
Activity 11	Moving around	<p>This activity assesses physical ability to move around outdoors. This includes ability to transfer unaided between two seated positions, to move up to 50 metres, up to 200 metres and over 200 metres. Factors such as pain, breathlessness, fatigue and abnormalities of gait are taken into account when assessing this activity. The descriptors reflect the use of manual aids such as sticks or prostheses, self-propelled wheelchairs and assisted aids such as electric wheelchairs.</p> <p>We envisage this activity applying to, for example, individuals with arthritis of the lower limbs, those with Chronic Obstructive Pulmonary Disease, multiple sclerosis which affects the lower limbs, generalised neurological conditions, quadriplegia and cerebral palsy.</p>
Notes	<p><i>This activity should be judged in relation to a type of surface normally expected out of doors such as pavements and roads and includes the consideration of kerbs.</i></p> <p><i>A short journey is up to 50 metres (approximately half the length of a football pitch) such that an individual is able to achieve a basic level of independence such as the ability to get from a car park to the supermarket.</i></p> <p><i>An extended journey is more than 50 metres but less than 200 metres (approximately twice the length of a football pitch) such that an individual is able to achieve a higher level of independence such as the ability to get around a small supermarket.</i></p> <p><i>Manual aids are aids or appliances that an individual is using to support their physical mobility which are unassisted – for example, walking sticks, crutches and prostheses but excluding manual wheelchairs or motorised aids.</i></p> <p><i>Assisted aids are wheelchairs propelled by another person or aids or appliances to assist propulsion that are powered by a motor – e.g. an electric wheelchair.</i></p> <p><i>Factors such as pain, breathlessness, abnormalities of gait and fatigue need to be taken into account</i></p>	

when assessing this activity. Where an activity can only be completed at the expense of excessive fatigue, the individual should be regarded as unable to complete it.

The person must be able to perform the activity safely and in a timely fashion - however, this only refers to the actual act of moving. For example, danger awareness (e.g. traffic etc) is considered as part of activity 10.

Descriptor (and notes)	Score
Can move at least 200 metres unaided or with the use of a manual aid.	A (0)
Can move at least 50 metres but not more than 200 metres either unaided or with the use of a manual aid.  (Identifies individuals who can move 50 to 200 metres unaided with or without the use of manual aids but have some limitation - for example, someone with severe arthritis of the lower limbs.)	B
Can move up to 50 metres unaided.  (Identifies individuals whose mobility is severely restricted and do not or cannot use aids and appliances - for example, someone with severe Chronic Obstructive Pulmonary Disease. Includes individuals who can move up to 50 metres but then require a wheelchair for anything further.)	C
Can move up to 50 metres only with the use of a manual aid.  (Identifies individuals who can use appropriate aids to move short distances unaided but have significant limitation - for example someone with multiple sclerosis affecting their lower limbs through increased tone and loss of coordination. Includes individuals who can move up to 50 metres but then require a wheelchair for anything further.)	D
Can move up to 50 metres only with the use of a manual wheelchair propelled by the claimant.  (Identifies individuals who can only move around with a self propelled wheelchair propelled by themselves.)	E
Can move up to 50 metres only with the use of an assisted aid.  (Identifies individuals who are reliant on motorised aids or physical support (such as someone pushing a wheelchair for them) such as individuals with a generalised neurological condition.)	F
Cannot either- i. Move around at all <b>or</b> ii. Transfer from one seated position to another seated position located next to one another unaided.  (Identifies individuals with severe disability such as quadriplegia or severe cerebral palsy where an individual cannot move 50 metres or cannot transfer unaided - for example, someone who is unable to get from a chair into a wheelchair by themselves.)	G

The focus on the medical model of disability – the concentration on solely the impact of impairment or condition – is explicit here. There is nothing to take into account wider social, practical and environmental barriers that inhibit disabled people from leading the types of lives they value.

Consider the first activity: planning and following a journey. The descriptors and notes that accompany them focus on psychological distress or the need for prompting and reminding. Many disabled people would be able to plan a 'complex journey' but would not be able to follow it – not because of psychological distress or because they need prompting, rather because the very modes of transport that would form part of the journey are inaccessible. Considering both Activities 10 and 11 together, a disabled person may well be able to plan a journey and to move between 50 and 200 metres (which is only half way around an athletics track), perhaps with the help of an aid, and yet could well score relatively low (A being zero points).

It is crucial here to consider the wider picture: what is PIP for? The policy objectives state the new benefit will be designed to support disabled people overcome the barriers they face to leading full and independent lives. If this is true, then there is a plethora of barriers that will not be captured by an assessment that concentrates solely on an individual's ability for movement or their ability to plan and follow a journey. Granted these descriptors will flag up some of the barriers, but will still show only a little of the whole picture. More importantly, considering a very limited range of barriers to getting out and about will not be of much help to identifying those individuals who would benefit most from additional support.

- **The scope of this part of the assessment is too limited to properly capture barriers to participation and leading a full and independent life.** This part of the assessment has an extremely narrow focus, which would not capture the barriers disabled people face to exercising choice and control and living the types of lives they have reason to value. For example, as stated in the activity notes: "This activity should be judged in relation to a type of surface normally expected out of doors such as pavements and roads and includes the consideration of kerbs".<sup>50</sup> Effectively this excludes disabled people from areas non-disabled people can easily access. Consider the example below:

*"[If I had more money] I would purchase a better electric wheelchair so I can go off-road, just like any abled bodied person."* – survey respondent, 2010

Similarly, limiting movement to ability to cover 200 metres – half an athletics track – with or without the use of a manual aid, suggests a very limited vision of the issues disabled people face when getting out and about.

- **The activities and descriptors make little allowance for disabled people and people with mental health conditions who face significant barriers from inaccessible public transport.** As already emphasised, one of the most frequent barriers disabled people and people with mental health conditions face in their everyday lives is that of inaccessible public transport – which, for many, means that they have to pay significant sums of money to take taxis or private transport to do the things they want to do.

*"If I have to go out but am not feeling well enough to drive then money has to be spent on taxis (£20 round trip just to get to my doctors' surgery or the dentist!!)..."* – Survey respondent, 2010

Other examples relevant were given earlier in the paper.

- **The activities and descriptors consider how disabled people use aids like wheelchairs, but only in relation to how they enable the individual to move around; for many disabled people, purchasing and maintaining such equipment can have significant impact on their disposable income and be a barrier to participation.**

*"It took me over for years to save enough money to purchase a hoist for my car and to buy electric add on wheels for my wheelchair. Without these items, I was unable to go out without help from somebody else."* – survey respondent, 2010

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<sup>50</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

### **Analysis of the assessment: a summary**

The Government is right to want to reform DLA from the overly complex, highly medical and deficit model focussed system of assessment that it is. The policy objectives of designing PIP so that it “supports disabled people overcome the barriers they face to leading full and independent lives”, and that “support is focussed on those with the greatest barriers” is very welcome and should be commended. However, as shown above, there are several serious flaws to the Government’s approach to the assessment, which will not only undermine the achievement of these objectives, but could have a very detrimental impact on disabled people – particularly those with low impact of impairment or condition, but who still face high barriers, and incur significant disability costs, which prevent them from leading the lives they value. In summary, these flaws are:

- **The assessment is highly medical, and not based enough on the social model of disability.**
- **The assessment will be of limited use in achieving the objectives of reform;**
- **Aims of achieving an assessment that is both totally ‘objective’ and accurate, and that achieve its original objectives for reform, contradict one another; and**
- **The criteria against which prospective recipients will be assessed is restricted to the point of being counter to the original purpose of both the new benefit and its predecessor.**

## The Future of PIP: an alternative vision

We support the Government's ambition of creating a benefit (in the form of PIP) to support disabled people overcome the barriers they face to leading full and independent lives. And yet, we do not believe that the Government's approach to DLA reform thus far does enough to achieve this aim. We believe that the basis for the assessment process is centred too much on the medical model of disability – focusing only on an individual's inability as a result of their "physical, mental or cognitive impairment with disabling effects".<sup>51</sup> As a consequence, it will only show a small part of the picture of the real barriers and disability-related costs disabled people and people with mental health conditions face, day in, day out.

Our preferred approach is an assessment that genuinely seeks to capture the barriers that a disabled person faces in their everyday life, and what effect these have on their capability for choice and control, participation and independence. With this in mind, set out below is an alternative vision for PIP – a new blueprint outlining what we believe the claimant pathway and the assessment process should look like. This model has been strongly influenced and informed by our own research with the think tank Demos; our discussions with disabled people; and the input and ideas we received during two days of workshops with a representatives from disability charities, disabled people's organisations, think tanks, academic institutions, information and advice charities, local authorities and transition services.

We have considered a variety of ways as to how best to capture information about the barriers a disabled person faces, and how they might be entitled to additional support from PIP. We recommend the trial of an approach that

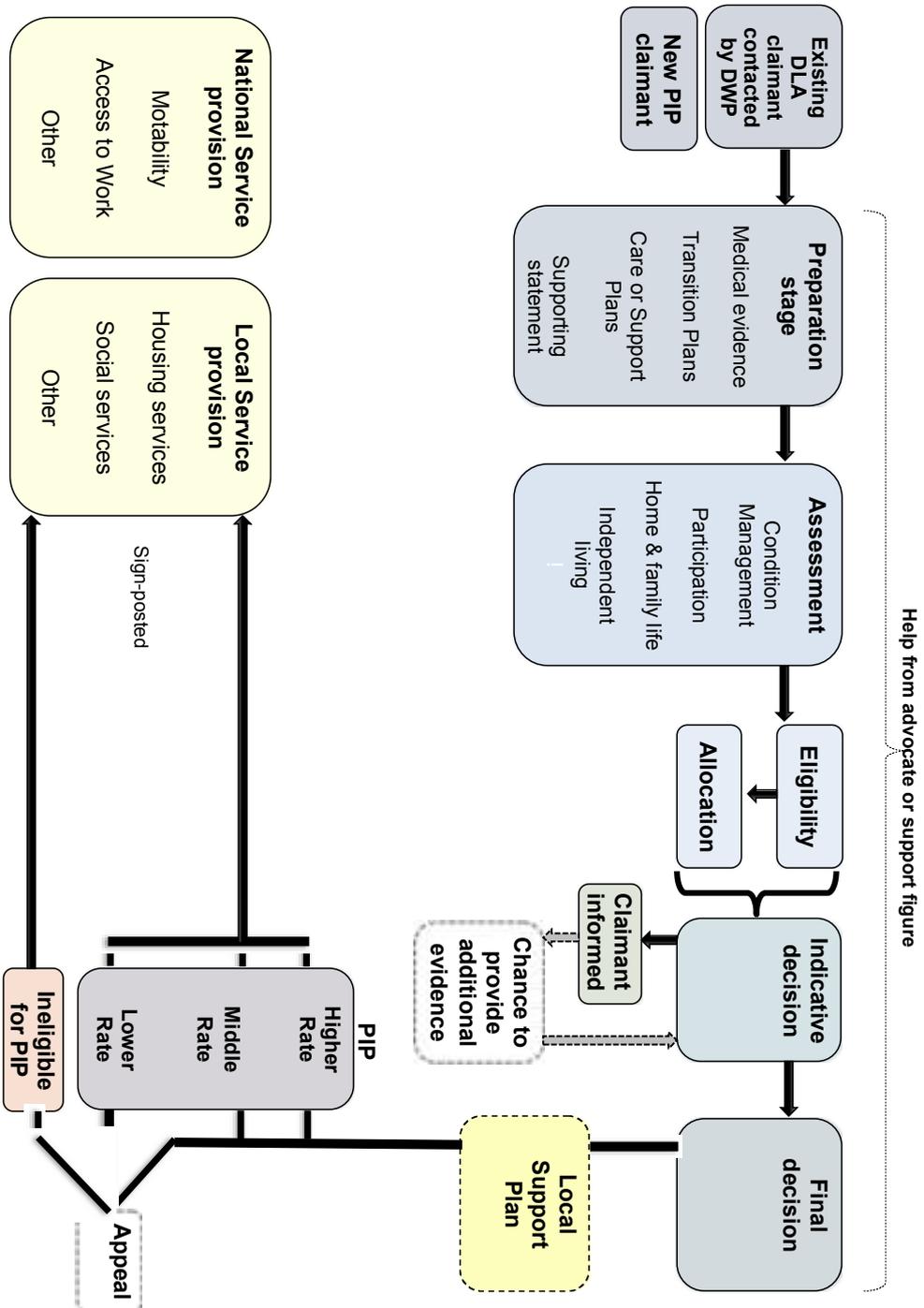
- **Takes greater account of the social model of disability**, by accounting for the social, practical and environmental barriers – and disability costs that come with these – as well as how an individual manages or copes with their condition or impairment;
- **Is co-produced with the claimant**, and not done 'to' them. We harbour serious concerns of the assessment for PIP making the same mistakes as those pointed out by Malcolm Harrington in his review of the WCA – that it is "impersonal" and "mechanistic" and "lacks communication" between the parties involved. We strongly believe that the PIP assessment needs to take the form of a conversation between the prospective recipient and the assessor, and believe there are very valuable lessons to be learned from person-centred planning, transition plans, and support plans used in Personal Budgets and Direct Payments.
- **Is better designed to helping disabled people overcome the barriers they face**, by ensuring that those facing significant external barriers, which could be reduced or removed by intervention from services (housing, for example, or Motability) are passported onto the relevant services. This already occurs in other assessments, and would be hugely beneficial to both the lives of disabled people receiving PIP, but, we believe, also to Government as the removal of barriers and costs would reduce the need for PIP, and ultimately lead to lower spending on the benefit over the long term.

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<sup>51</sup> DWP, *Personal Independence Payment: initial draft of assessment criteria - a technical note to support the initial draft of the assessment regulations*, May 2011, <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf> (accessed September 2011)

Adopting a new approach that includes the principles outlined above would notably change the process for claiming and receiving PIP. The diagram below is a blueprint that shows the stages such an approach could well incorporate.

### A Social Model Based Pathway For PIP



## 1. An initial preparation stage: collecting evidence of barriers and need

This section considers the need for an early collection of evidence that would be relevant and beneficial to both the prospective recipient and the assessor. The recipient – having newly applied for PIP or having been informed of a forthcoming assessment as result of being migrated from DLA to PIP – undergoes an initial preparation stage during which they would be able to submit existing evidence that would help to highlight the barriers to independence and participation that they face. Such evidence could take the form of a transition plan, a support plan (for those who receive a Personal Budget), a care plan, evidence from their GP (although, many GPs charge for this service) or other form. None of these would be obligatory, but would help highlight the barriers they face, the needs they face, and the support systems – or lack thereof – that they have in place.

Such evidence could then used as the basis for conversation between the assessor and the prospective recipient when they get to the assessment stage. The benefits of including this stage would be two-fold: it would help the claimant prepare for the assessment; and would also potentially save costs by making the assessment itself more time efficient as many of the barriers have already been brought to the assessor's attention. It is important to note that a prospective recipient who does not – or is unable to – provide such evidence would not be disadvantaged; simply that the assessment itself would take a little longer in order to identify from scratch where the barriers to participation and independence arise in their life.

Finally, the introduction of a proper preparation stage would allow the recipient to access advocacy support such as an individual or a group; peer support network; formal, professional, paid, legal or citizen advocacy; a support or key worker; friend, neighbour or family member, or anyone else. **We recommend that the DWP directly inform the prospective recipient – via the letter that informs an existing DLA claimant of a future PIP assessment, or when contacted by a new PIP claimant – of the option of finding a support figure with whom they can undergo the assessment process.**

## 2. A more multidimensional assessment that places greater emphasis on the social model of disability

As the evidence, examples and arguments set out in this paper serve to demonstrate, the principles underlying the assessment – and the activities and descriptors contained within – need to be reconfigured if the test for PIP is to enable the Government to achieve its objectives of supporting disabled people overcome the barriers they face to leading full and independent lives; ensure that support is focused on those with the greatest barriers; and to produce an assessment that assesses, among other things, “those people who would benefit most from additional support”.

We believe that, in order to achieve these objectives, the assessment needs to

- **Consider the impact of impairment(s) or health condition(s) in terms of condition management** – in other words, how the individual manages their impairment or condition on a day-to-day basis, what their coping strategies are and what support they get from other people (if any); **and**

- **Consider the external barriers – be these social, practical, environmental or other – that prevent the individual from exercising choice and control, and leading a full and independent life.**

To do this, we believe the assessment needs to combine a points-based descriptor approach *and* that of a broader, more qualitative approach similar to that used in the assessments for Personal Budgets.

With this in mind, a more multidimensional, social model-based approach to assessing eligibility for PIP might seek to capture the following information via the means outlined below.

(Note: what is suggested below is but a draft blueprint for what we believe would be a more social model based, multidimensional assessment. However, further development, testing and trialling are needed to improve and refine the criteria suggested.)

- **Details of general circumstances** (name, address, dob, NI number, etc.). In addition to more generic personal and contact details, this part could also be designed so as to capture the individual's living situation – whether they live alone or with family, friends, partner, etc.; whether they have someone who looks after them (formally or informally). This would help capture information about the prospective recipient's living status – and any existing (in)formal support network, which we know has a real impact upon the barriers and disability-related costs that a disabled person faces.
- **Information about current difficulties and issues they are experiencing:** This would allow the prospective recipient to here explain why they have applied for PIP. A free-text box – filled in by the assessor and the claimant could help capture vital information about the barriers a disabled person faces in their everyday life, with the aim of helping the assessor identify whether they would benefit from additional support and other areas to discuss later in the assessment. This kind of information is already captured in Self Assessment Questionnaires (SAQs), and there is no reason as to why this could not be included in a future PIP assessment.
- **Weekly activities:**  
In this stage the assessor would aim to get a clear picture of
  - ⇒ How they manage – their needs and coping strategies;
  - ⇒ How and if they are supported, and, if so, in what way;
  - ⇒ The barriers they face when undertaking the activity; and
  - ⇒ How they would like to be able to do the activity; what would make their life easier.

Our research shows there to be a plethora of activities in which disabled people and people with mental health conditions face significant barriers, and extra disability costs. From our discussions with experts and representatives from a range of sectors – including DPOs, social care and welfare benefits, disability charities, academia and think tanks – we believe that the vast majority of these activities can be placed into one of four categories:

- **Condition Management and Wellbeing:** activities and barriers in this category revolve around how a disabled person or person with a mental

health condition currently manages living with their condition or impairment; what they have to do to endure pain, discomfort, etc.; what strategies and support systems they have in place for coping with the adverse effects of their impairment or condition. For example, this might include having to have the heating on to keep warm to prevent the body from going into spasm, having to pay for therapies – prescribed and un-prescribed – that helps the individual cope on an everyday basis.

*“I would like to pay for private therapy, as I am very unhappy with the lack of therapy for severe mental health problems in my area... I would like to investigate meditation or yoga lessons to improve my mental health.”*

- **(Social, cultural, economic, religious/spiritual) participation:** barriers that may be considered to fall into this category include those that inhibit or prevent a disabled person from being capable of participating in the social, cultural economic (e.g., employment, volunteering, etc.), religious or spiritual activities that they want to participate in.

*“Public transport is difficult to manage in busy cities with buses stopping and starting all of the time. This means that I have to rely on taxis. These make the cost of socialising much higher than those of my sighted friends who can just walk to an event or use public transport. I think that this is primarily where my extra costs are focussed.”*

*“Being able to afford a taxi to 'go out' (and come back) on a regular basis would liberate disabled people to 'enjoy' a social scenario without fatigue compromising every situation.”*

- **Home and family life:** barriers in this category can obstruct disabled people from reaching their potential to meet family responsibilities. For example, many of the respondents to our 2010 survey pointed out that, because of their health condition or impairment, they were too tired after work to look after their children or carry out other family duties. Similarly, a disabled person who experienced real barriers (arising from their impairment or an external factor like unsuitable housing) to maintaining a family home (cooking for a family, for example) may then have to pay for someone else to help them with this, which could have a dramatic effect on their disposable income.

*“I don't have enough money to make my home wheelchair accessible nor can I afford to fund adaptations in my kitchen therefore I cannot reach the side to cook/prepare food.” – survey respondent, 2010*

*“I use my DLA to pay for my ironing and buy gifts for my family who help with cooking and cleaning and doing tasks when I am too tired or my limbs are not fully functioning. Usually at the end of the day having been at work all day!”*

- **Independent Living:** many of the barriers disabled people face in their lives affect their ability to live as independently as possible – and often have to rely on friends and family or formal carers in order to keep living independently. Many of the activities in this category revolve around simple, but important household tasks. As many disabled people need help with these (but may not be eligible for assistance in the form of social care) they can face real barriers to maintaining their home environment, and often have to pay extra disability costs to get outside help with simple household tasks.

*“I can only afford my cleaner/assistant for 4 hours once a week. Midweek, I have to do some things like wash up the glasses, or take out the recycling, which is*

*painful for me. My husband can do some things but not all because he is at work before I'm awake and tired when he gets home at 7pm. I'd like to be able to hire my assistant twice a week but cannot afford to do so, which means I have to struggle on. It's also unfair how much my husband has to do, when he is out at work 5 days a week already!"*

*"Things definitely cost more when disabled, as people with disabilities often have extra costs as a result of their condition... If I had more spare money I would pay for someone to come into my home and help me with domestic and personal tasks."*

Attempting to design descriptors that could capture the whole range of activities, and connected costs, that a prospective claimant undertakes as part of their daily life, could potentially make the assessment overly complex and unwieldy. So as to overcome this problem, it is suggested here that **the assessor gets the claimant to provide information about the activities that are important to them themselves**, and then to ask a series of probing questions that would capture information on:

- ⇒ The way in which the person carries out the activity;
- ⇒ How they usually manage when doing so;
- ⇒ How – if – they are supported, in what way, and by whom; and
- ⇒ How they would like to be able to do the activity in question.

The process could then be repeated for several activities, one of which would ideally fall into one of the four categories outlined above (in other words, how the disabled person manages their condition; what barriers to they face to participation; what issues arise as a direct or indirect result of their impairment or condition when trying to meet family responsibilities; and, what difficulties they experience to living as independently as possible.)

They would be scored according to the impact of certain barriers – both as a direct result of their impairment or condition and as a result of external factors like inaccessible transport, inadequate housing or lack of support networks. They would receive an amalgamated score across barriers, which would determine their eligibility for PIP, and whether this would be for a single higher, middle or lower rate.

**We do not believe dividing PIP into Daily Living or Mobility components fits in with a social model approach or the four categories suggested here. Rather we suggest there be one PIP payment, available at three different rates (low, middle and higher).** The decided rate would be indifferent to the barriers the individual faces, but would be representative of their overall score across these barriers.

Finally, we do not believe it is our place to suggest the scoring rate or what scores should be assigned. Rather this should be developed and refined with further trialling and testing. However, we would argue for a flexible system – which could be recalibrated and adjusted as testing, trialling and, eventually, rollout is in place.

## What might a more multidimensional assessment look like?

- In terms of the actual assessment, one means to this end would be to get the prospective recipient to **talk the assessor through a typical week and the sorts of things they like to do**;
- The assessor could then pick up on several activities (at least one in each of the four categories mentioned above) and explore each one in terms of
  - ⇒ How the prospective recipient carries it out;
  - ⇒ How they usually manage, when doing so; and
  - ⇒ How – if – they are supported and in what way;
  - ⇒ How they would like to do the activity.
- This would allow the prospective recipient to give the assessor a much better picture of the barriers (and costs) they face in trying to lead the lives they value.
- Using this information, the assessor could then give the individual a series of scores based on their level of needs and internal (*i.e.*, in relation to managing a health condition or impairment) and external (*i.e.*, in relation to social, practical and environmental factors like unsuitable housing, inaccessible transport, social isolation and no network of support, etc.)
- Scores would be assigned points. A higher level of points would indicate a higher level of needs to overcoming barriers and meeting disability-related costs. The higher up the spectrum a claimant scored, the greater the likelihood they would be entitled to PIP.
- At the end, the assessor would then need to flag – according to information that is captured in the assessment – whether they think the claimant would benefit from additional support from *other* services – occupational therapy, social care assessment, Access to Work, etc. It would be the assessor's duty to the signpost the claimant onto those services whose intervention seemed to be warranted. (See below for more on signposting).

## Who would need to be there?

It is very important that the individual undergoing the assessment feels supported during the process. Being able to access advocacy support - from sources such as an individual or a group; peer support network; formal, professional, paid, legal or citizen advocacy; a support or key worker; friend, neighbour or family member, or anyone else – would, we believe, help build empathy in the process, but also would allow the advocate to input into the process so as to provide any necessary prompts, extra information or clarifications, which would enable the assessor to get as clearer a picture as possible.

## Who should do it?

An assessment based on the social model of disability needs to be carried out by appropriately selected assessors with expert knowledge of the barriers disabled people face. If DLA reform is to be centred on the social model of disability, we do not believe it is appropriate for assessments at the centre of this

reform to be conducted by medical professionals. The roll out of the personalisation agenda has resulted in wealth of professionals who we believe would be better placed to carrying out an assessment of the type suggested here. These could be experts with experience in person-centred planning, transition plans, support plans, social care, and other areas (which would be expanded and refined with testing and trialling.)

### 3. Eligibility and rate → indicative decision

Following the assessment, the assessor would tell the prospective recipient about the likely outcome of their assessment. At this point, they would be able to provide extra information that they felt might be of relevance to the outcome of the final decision. They would have to do this within a specific timeframe – for example, within 10 days of being informed of the indicative decision.

Including this stage, we believe, would significantly improve the transparency of the assessment process, as well as improve the lines of communication between the assessor and the claimant. Ultimately, we think that sharing in advance the penultimate results with the claimant would help lower the number of final decisions that are taken to appeal – an outcome that would help lower costs for Government, and could make the application process less arduous and stressful for the disabled person themselves.

As well as being informed as to their eligibility, those claimants who, at this point, were deemed entitled to PIP, would then also be informed of their indicative allocation - what rates they were entitled to (lower, middle or higher.)

### 4. Final decision

The claimant is then informed of the full outcome of the assessment, as decided by a DWP decision-maker. Should they wish to challenge the decision, they can appeal. At this stage, all applicants – successful or not – would receive a **Local Support Plan**, which would capture the evidence and information brought up over the course of the assessment process, and which would help highlight where in the individual's life their barriers and their needs tend to arise. This could help the claimant identify particular areas in which PIP might provide valuable support meeting disability costs, but would **not** take the form of an outcomes-based agreement (binding the individual to use their PIP for specific purposes). Moreover, it would be used to flag where in their life additional support from national and local services could help with reducing or removing long-term barriers. The claimant would be passported to a local triage solution, as the plan would show what support they could do with in their community. This would be of benefit to everyone who undergoes a PIP assessment, as some may not be considered entitled to PIP, but may well be thought to benefit from help from such services.

### 5. Signposting to other support services

At the end of the assessment, the assessor should have flagged whether they thought the claimant would benefit from additional support *besides that provided by PIP*. A more social model-based, multidimensional assessment should capture information about the external barriers the claimant faces, and the assessor should then decide as to whether intervention from statutory or non-statutory services would help lower or remove barriers and improve the claimant's capabilities for independence in the long-term.

This part of the assessment would fit well with the Government's localism agenda, as it would show what support a person could do with in their community and passport them to a local triage solution.

## **6. Reassessment**

The Local Support Plan would store the information captured in the assessment, as to where particular barriers and disability costs inhibit independence and choice and control. Having this information in one place would then inform when the claimant's next assessment happens, as well give an indication as to what this may cover. This is in recognition of the fact that an individual's personal circumstances may change and, in doing so, have a direct impact upon the barriers they face and disability costs they incur. For example, a disabled adolescent making the move from residential or familial care into independent living would be sure to face very different barriers and costs as a result of such a move than he or she did before. This forthcoming event could be captured in their Local Support Plan, in which there could then be set a date – agreed by the claimant and the assessor – when the individual is reassessed so as to determine whether the barriers they face have increased.

## **7. Verification**

An assessment process based on the social model of disability needs a less medical system of verification. While we would be very quick to point out the extremely low (0.5%)<sup>52</sup> levels of fraud for DLA, we understand the Government's concerns about verification. Yet, we strongly believe that it is not appropriate to revert back to the medical model in this instance, and so we suggest that the prospective recipient is made to submit – during the initial preparation stage – a supporting statement in the form of a reference from an eligible profession (the list of which could be expanded and refined during the testing and trialling process) – as similarly used with applications for official documents like passports, etc.

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<sup>52</sup> <http://research.dwp.gov.uk/asd/asd2/fem/nsfr-final-120711.pdf>

### Example 1 – (indicative only)

General details	
Title:	<input type="checkbox"/> Mr <input type="checkbox"/> Mrs <input type="checkbox"/> Ms <input type="checkbox"/> Miss <input type="checkbox"/> Other
DOB:	_____
First name:	_____ Surname: - _____
Address:	_____
Postcode:	_____
Tel:	_____
Who do you live with?	<input type="checkbox"/> Alone <input type="checkbox"/> Partner <input type="checkbox"/> Friend <input type="checkbox"/> Spouse <input type="checkbox"/> Other
Do you have any dependents?	<input type="checkbox"/> None <input type="checkbox"/> Partner <input type="checkbox"/> Parent <input type="checkbox"/> Children (<18) <input type="checkbox"/> Other
If you have a dependent, do you have to provide support to them?	<input type="checkbox"/> Yes <input type="checkbox"/> No

This section above would help capture information about the prospective recipient's living status. It would capture some initial information about the individual's immediate support network, but would also give an indication as to whether the assessor might need to discuss the individual's home and family – to identify any barriers and costs that arise here.

What are your reasons for contacting us? What barriers do you currently face?
[Free text box] [To be filled out by the assessor and the claimant]

Here the recipient could explain why they have applied for PIP and give an initial indication of the barriers and problems they currently face. This would help the assessor in identifying whether the individual would benefit from additional support, but could also flag up certain areas of the claimant's life in which they face particular barriers. For example,

*"I would like to pay for private therapy, as I am very unhappy with the lack of therapy for severe mental health problems in my area. I would also like to investigate meditation or yoga lessons to improve my mental health."* – survey respondent, 2010

An assessor might then be able to pick up on these later in the assessment. In this case, how the individual manages their mental health condition; what impact activities like meditation might have on their capability for condition management.

As well as the information captured here, an assessor should draw upon any of the relevant information that may have been provided prior to the assessment – during the preparation stage.

**How do you spend your day and your week? What do you usually do?**

[Free text box] [To be filled out by the assessor and the claimant]

This stage would centre on the claimant providing information as to the kinds of things they do in their lives – the kinds of activities that are important to them. For example (participation),

*“I like to go to shows and museums.”*

The assessor might then ask a series of probing questions that would then highlight how the individual carries out the activity/activities, how they usually manage, and how (if) they are supported. For example,

*“I like to do lots of activities, and someone, sometimes two people have to accompany me, it cost the price of three people for tickets average 60 pounds for shows and the transport costs for the two people accompanying me, also food for two extra people because I cannot go out alone.” – survey respondent, 2010*

In this example, the answer would then flag up how the individual manages (in this case, by needing one or two people to accompany them) and what barriers they face (having to pay for one or two extra tickets, food, etc.)

This could then be scored according to need for and access to networks of support.

<b>Activity Level of support needed</b>	<b>E.g. Show/museum</b> [To be filled out by assessor and the claimant]	<b>Score</b>
	I complete this activity without any need for support and assistance	<input type="checkbox"/> A
	I sometimes need support when carrying out this activity	<input type="checkbox"/> B
	I always need support when carrying out this activity	<input type="checkbox"/> C

<b>Activity Access to support needed</b>	<b>E.g. Show/museum</b> [To be filled out by assessor and the claimant]	<b>Score</b>
	Receives informal support from friend, family, neighbour etc.	<input type="checkbox"/> A
	Pays for formal support from carer, support worker, etc.	<input type="checkbox"/> B
	Has no access to support needed	<input type="checkbox"/> B

Having established a key activity that is important to the individual – going to a museum, for example – and also having established how they manage – by having a person(s) accompany them – the assessor would then seek to establish if and how the individual is supported, the type of support they receive, and the extent to which they can access this. When considering the type of support they receive, it is very important to be mindful of the fact that paying family and friends who give informal support is still a significant disability-related cost; people with access to support from family and friends should not be denied support simply because they receive informal assistance, as this can be a key driver of disability costs. Furthermore, it is also critical to capture the *need for support*, rather than whether or not they receive it: an

individual may have developed certain ways of managing to carry out an activity, but extra support would be of huge benefit and lead to better outcomes for their capabilities, health and wellbeing, as well as their safety.

<b>Activity</b>	<b>E.g. Swimming</b> [To be filled out by the assessor and the claimant]
<b>How would you like to be able to this?</b>	
[Free text box] [To be filled out by the assessor and the claimant]	

This part could help the assessor identify whether and how the individual would benefit from receiving PIP – how additional support would allow them to overcome the barriers to this activity so that they can exercise greater choice and control by doing it in the way they want to be able to do. For example,

*“I would so love to go out and have a good time with friends in their houses. If I could just have an electric wheelchair I'd feel more independent out there in the world.” – survey respondent, 2010*

### **Example 2 – (indicative only)**

<b>How do you spend your day and your week? What do you usually do?</b>
[Free text box] [To be filled out by the assessor and the claimant]

Returning to the original question, the assessor could then pick up on another activity that the individual does or feels is important to them. For example (independent living),

*“Eating good food helps me retain my energy levels.” – survey respondent, 2010*

Again, the assessor might then ask a series of probing questions that would then highlight how the individual carries out the activity/activities, how they usually manage, and how (if) they are supported. For example,

*“I spend the extra money I receive on paying for good quality food (such as Marks and Spencer Soup), which is healthy but also easy to prepare (as I often spill what I'm working on, and when tired can't control my limbs properly, so food preparation takes a long time and I cut myself a lot!)” – survey respondent, 2010*

Then in addition to asking questions about the individual's need for and access to support, the assessor could then seek to determine whether their housing is suitable for their needs, and probe for information to this end. For example,

*“I don't have enough money to make my home wheelchair accessible nor can I afford to fund adaptations in my kitchen therefore I cannot reach the side to cook/prepare food.” – survey respondent, 2010*

This could be scored on a scale like the example given below.

Activity	E.g. Cooking [To be filled out by the assessor and the claimant]	Score
Housing	No housing related barriers	<input type="checkbox"/> A
	Location of housing is a barrier to carrying out activity independently	<input type="checkbox"/> C
	Accessibility of housing is a barrier to carrying out activity	<input type="checkbox"/> C
Housing/ Managing condition or impairment	Suitability of housing is a barrier	<input type="checkbox"/> C
	Heating of housing is a barrier	<input checked="" type="checkbox"/> C

Activity	E.g. Cooking [To be filled out by the assessor and the claimant]
<b>How would you like to be able to this?</b>	
[Free text box] [To be filled out by the assessor and the claimant]	

This part could help the assessor identify whether and how the individual would benefit from receiving PIP – how additional support would allow them to overcome the barriers to this activity so that they can exercise greater choice and control by doing it in the way they want to be able to do. For example,

*“I would turn the heating on more. I cannot afford to keep my home properly heated and the cold causes a lot of pain which in turn has an impact on how effectively I can work...”*

With this information, an assessor might then ask condition management related questions, which would enable them to find out about the barriers that arise for the individual from managing their condition or impairment.

Condition Management Needs	Status	Score
	Managing my condition is never a barrier to doing what I want to do	<input type="checkbox"/> A
	Managing my condition sometimes a barrier to doing what I want to do	<input type="checkbox"/> B
	Managing my condition is always a barrier to doing what I want to do	<input type="checkbox"/> C

### Example 3 – (indicative only)

How do you spend your day and your week? What do you usually do?
[Free text box] [To be filled out by the assessor and the claimant]

Returning to the original question, the assessor could then pick up on another activity that the individual does or feels is important to them. For example (participation),

*"We have weekends away to see friends as long as their houses are suitable."* – survey respondent, 2010

Again, the assessor might then ask a series of probing questions that would then highlight how the individual carries out the activity/activities, how they usually manage, and how (if) they are supported. For example,

*"I have various friends who pay for outings and are very generous with gifts of the niceties of life that I cannot afford."* – survey respondent, 2010

This answer – and information from a follow up question – would help the assessor assess the need for and access to support (as part of establishing the extent of the individual's support network (or lack thereof).

Activity	E.g. Seeing friends [To be filled out by the assessor and the claimant]	Score
Level of support needed	I complete this activity without any need for support and assistance	<input type="checkbox"/> A
	I sometimes need support when carrying out this activity	<input type="checkbox"/> B
	I always need support when carrying out this activity	<input checked="" type="checkbox"/> C

Activity	E.g. Seeing friends [To be filled out by the assessor and the claimant]	Score
Access to support needed	Receives informal support from friend, family, neighbour etc.	<input checked="" type="checkbox"/> A
	Pays for formal support from carer, support worker, etc.	<input type="checkbox"/> B
	Has no access to support needed	<input type="checkbox"/> B

Then in addition to asking questions about the individual's need for and access to support, the assessor could then seek to determine whether transport is a barrier to exercising choice and control, and undertaking the activity.

This could be scored on a scale like the example given below.

Activity	E.g. Seeing friends [To be filled out by the assessor and the claimant]	Score
Transport	Public transport is inaccessible	<input type="checkbox"/> C
	Public transport is accessible	<input type="checkbox"/> B
	Has access to alternative modes of transport (personal – e.g. family and friends' vehicles)	<input type="checkbox"/> B
	Has to use alternative modes of transport (private – e.g. taxis)	<input type="checkbox"/> C

Taken together, from the information captured here the assessor should get a clearer picture of the barriers a disabled person faces to undertaking the chosen activity. For example, someone who needed to support to undertake the activity, but who was not inhibited from using public transport, could still incur additional barriers from having to pay for travel costs of the person providing the support.

*"If I want to go anywhere with an entry fee or ticket I have to buy two if my sister cannot come with me I have PA costs. I used to have council care but still ended up paying PA costs if I want to go out at night."* – survey respondent, 2010

Activity	E.g. Seeing friends [To be filled out by the assessor and the claimant]
How would you like to be able to this?	

[Free text box] [To be filled out by the assessor and the claimant]

This part could help the assessor identify whether and how the individual would benefit from receiving PIP – how additional support would allow them to overcome the barriers to this activity so that they can exercise greater choice and control by doing it in the way they want to be able to do. For example,

*“If I had more money, I could be more independent and be able to afford to take taxis for social and business reasons, rather than having to rely on friends for transport.” – survey respondent, 2010*

### **Signposting to other support services**

At the end of the assessment, the assessor should have flagged whether they thought the claimant would benefit from additional support *besides that provided by PIP*. A more social model-based, multidimensional assessment should capture information about the external barriers the claimant faces, and the assessor should then decide as to whether intervention from statutory or non-statutory services would help lower or remove barriers and improve the claimant’s capabilities for independence in the long-term.

#### **Additional support required?**

- Occupational Therapist Visit**
- Access to Work**
- Blue Badge Scheme**
- Motability**
- Social Care Assessment**
- Mental Health Assessment**

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